BARRIERS AND FACILITATORS TO HEALTH AND SOCIAL CARE FOR BME SERVICE USERS AND CARERS WITH RARE NEURODEGENERATIVE CONDITIONS

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ABSTRACT

Background: Although ethnic inequalities have been widely researched in many areas of health, barriers and facilitators to health and social care services for BME service users and carers with rare neurodegenerative conditions have not been researched.

Aim: To identify the barriers and facilitators to health and social care for BME service users and carers with rare neurodegenerative conditions.

Methods: 15 qualitative semi-structured interviews with service users and carers with motor neurone disease (MND), Huntington's disease (HD), post-polio syndrome (PPS), multiple system atrophy (MSA), and Charcot Marie Tooth disease (CMT).

Results: Pathways to care are described and barriers and facilitators that service users faced. Barriers included language, expectations of services, knowledge of services. Service users and carers also experienced isolation and stigma. The main facilitator to care was having a care co-ordinator.

Conclusion: Although some of the barriers to care were specific to BME service users and carers, many of the barriers could have been faced by all service users with rare neurodegenerative conditions.

PUBLISHED WORK

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1. INTRODUCTION

It is well established that significant and far-reaching inequalities exist within the UK healthcare system (Acheson 1998;Black et al. 1980;Marmot et al. 2010). In the National Health Service (NHS), these inequalities can influence access to healthcare professionals, affect the ability of individuals to obtain clinical referrals and appropriate diagnostic tests, and impact upon the quality of ongoing treatment and management for patients who have been diagnosed with long-term and chronic conditions in particular (Allerton and Emerson 2012;Elkan et al. 2007).

One of the first reports to highlight issues of health inequalities was the Black Report (Black, Morris, Smith, & Townsend 1980) which found evidence of health inequalities despite the existence of the welfare state and the fact that one of the key founding principles of the NHS was that it should 'meet the needs of everyone'. One of the key areas of inequality noted by the report was the finding that non-White Britons had higher rates of mortality and morbidity than their white counterparts, largely because they had higher representation in the lower social classes, where inequalities were found to be particularly pronounced. The report noted that at the time, official statistics rarely included data on ethnicity, as this was not routinely collected or readily available. Consequently, the recommendations from the Black Report did not specifically mention tackling ethnic inequalities, but instead stated that children should have a better start in life, more preventive and health education should be encouraged, and that quality of life for disabled people should be improved (Black, Morris, Smith, & Townsend 1980). It was believed that in combination, these

recommendations would reduce the inequalities in health that the report had highlighted. The Acheson Inquiry (1998) and the Marmot Review (2010), despite being written 18 and 30 years respectively after the Black Report, stated that ethnic inequalities in health still existed, and that far from improving, in many cases, inequalities were becoming more evident over time and the health inequality gap was steadily widening. Once again, members of BME groups and those living in economically deprived areas were noted as being particularly likely to experience health inequalities.

The Government responded to the existence of these health inequalities by introducing policies to ensure that all public bodies had a duty to provide equitable services. Saving Lives – Our Healthier Nation White Paper (Department of Health 1999) was developed in direct response to the Acheson Report (1998) as was the NHS Plan (2000). More recently, Healthy Lives, Healthy People (Department of Health 2010) was proposed by the current Government as a method for tackling health inequalities. It drew on research findings that members of BME groups were significantly more likely than the national average to be affected by infant mortality, childhood obesity, and to suffer with mental health issues. The Equality Act 2010 (Great Britain Parliament 2010), and the Race Relations (Amendment) Act 2001 (Great Britain Parliament 2001) both emphasised that public bodies including health and social services were required to provide equal services to everyone and without discrimination.

Although clear differences are evident in health status between and across ethnic groups, the extent to which these differences can be attributed directly to failings in the provision of healthcare or by other factors such as socio-economic deprivation or societal racism is unknown. Collection of ethnicity data has been an important part of tackling inequalities within the NHS, and has been mandatory since 1995. However, a survey by Aspinall (2000) found there were high levels of missing data (Aspinall 2000). Although the collection of ethnicity data has improved, the Equality Act 2010 has reinforced this by making it a statutory requirement for health and social care providers to collect ethnicity data.

There is, however, clear evidence that people from minority ethnic backgrounds are less satisfied with the NHS than others (Campbell et al. 2001;Mead and Roland 2009;Raleigh et al. 2010). NHS patient surveys reveal, for example, that people from Indian, Pakistani and Bangladeshi groups report a poorer experience than people from the White British group. But it is not clear where in the NHS system minority ethnic patients are experiencing unfair or inequitable treatment; what the nature of the unfairness is; which groups are most affected, and the extent to which ethnicity is the issue over and above socio-economic deprivation.

NHS organisations are bound by law to publish Race Equality Schemes to ensure that their services are serving all members of the community, and there are various programmes under way across the NHS to ensure greater fairness in access. However, there is a general lack of evaluation of such projects, as well as gaps in

research on the exact nature of problems of access and how services can be improved to reduce some of this disadvantage.

Some work has been done on identifying whether ethnicity data collection is sufficient by health and social care providers to identify where ethnic health inequalities exist and what their root cause(s) might be (Aspinall and Jacobson 2007;Sultana and Sheikh 2008). Aspinall and Jacobson (2007) found that ethnicity data collection varied amongst different healthcare providers and that led to few datasets that contained robust ethnicity information. Iqbal et al (2012) interviewed healthcare workers to identify whether they routinely collected ethnicity data, and how they collected it. They found that some healthcare workers were reluctant to collect ethnicity data because they did not understand the importance of collecting that data, or because they were worried about service users' response to these questions (Iqbal et al. 2012). Therefore, to improve the collection of this data, training needs to be provided to healthcare workers not only on how to collect the data, but also why it is being collected, and how it could be used to improve services. Some studies have made use of ethnicity data and have examined surveys or routinely collected information to find out whether there are differences in healthcare between different ethnic groups, and where the differences are (Addo et al. 2011;Alshamsan et al. 2012;Lyratzopoulos et al. 2012;Nazroo et al. 2009;Nimako et al. 2013). Nimako et al (2013) analysed data from 423 patients with lung cancer at a large hospital and found that although BME service users were over-represented in the lower socio-economic groups, ethnicity did not make a difference to the treatment received, or to survival rates. This suggests that the services provided were equitable, and that

whatever policies were in place were working. This does not always happen, and interventions to reduce disparities specifically do not always work. Alshamsan et al (2012) analysed Quality and Outcomes Framework (QOF) data, and found that QOF did not reduce inequalities in diabetes outcomes for members of BME groups. Surveys have shown that people from Indian, Pakistani and Bangladeshi backgrounds generally report poorer NHS experiences and poorer health than their white counterparts (Campbell, Ramsay, & Green 2001;Johnson et al. 2000;Mead & Roland 2009). But again, it is often unclear where in the system BME patients are experiencing inequitable treatment. For example, Nazroo et al (2009) analysed four successive rounds of the Health Survey for England (HSE) and found that BME service users were equally likely to use primary care services as White British service users, but that inequalities existed in using secondary care services. Therefore, identifying that inequalities exist and where they exist are important issues, but equally important is to find out why they exist and what can be done to address them.

There have been a number of studies to examine barriers and facilitators to health and social care for BME service users and carers with a variety of conditions in a number of settings. These include cancer (Randhawa and Owens 2004), maternity care (Edge 2010;Raleigh, Hussey, Seccombe, & Hallt 2010), palliative care (Badger et al. 2012), dementia (Mackenzie 2006;Turner et al. 2005), cardiac rehabilitation (Chauhan et al. 2010) and incontinence (Doshani et al. 2007). All of these studies provide interesting insights into barriers and facilitators experienced by BME service users. The most common barriers to care are language, awareness and knowledge of services, and cultural factors, sometimes related to stigma. These barriers to care

are not isolated, rather there is overlap between all of them. Moffatt and Mackintosh (2009) interviewed BME elders in Newcastle and found a number of barriers to claiming benefits, including lack of knowledge and language(Moffatt and Mackintosh 2009). However, they also reported that stigma was attached to claiming benefits. Language barriers were sometimes directly linked to lack of information about services. For example, Ochieng (2013) reported on the experiences of Black African migrant families' experiences of accessing health promotion information and found that lack of literacy prevented some from accessing health information(Ochieng 2013). However, Lui et al (2012) found that health promotion interventions that were successful in the general population were also successful in the BME population if they were adapted and targeted appropriately (Lui et al. 2012). This suggests that it is possible to utilise strategies to combat inequalities for health promotion, but despite policy encouraging services to provide equal access to care, these barriers still exist.

In addition, there is some evidence to suggest that health professionals do not feel equipped to deal with service users from minority groups. Almond and Lathlean (2011) found that although there was policy in place to provide equitable services to minority groups, the policy was not being followed (Almond and Lathlean 2011). This suggests that initiatives taken by health and social care services to improve service access have not been successful for a variety of reasons, including lack of staff training. Chapter 2 provides a more detailed description of the literature.

1.1 Rationale and clinical focus

This study was part of the Result Study (Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions), and this study was tasked to identify access to care for BME service users because none of the studies undertaken to date have focussed on barriers and facilitators to care for BME service users with neurodegenerative conditions. The Result Study was funded by the Policy Research Programme for Long Term Neurological Conditions (Department of Health). These conditions are linked by damage to the nervous system either by cell degeneration or trauma that can then lead to severe impairment. Allerton and Emerson (2012) performed a secondary analysis on the Life Opportunities Survey and found that those that reported having impairments faced more difficulty in getting appointments, they reported transport as a barrier to care, and reported that their information needs were not met. Therefore, BME service users with neurodegenerative conditions could be faced with these barriers to care in addition to the language, information awareness, stigma and cultural barriers they potentially face already.

This study focuses on a number of neurodegenerative conditions, some of which are more prevalent than others. The conditions that were chosen were Motor Neuron Disease (MND), Huntington's Disease (HD), post-polio syndrome (PPS), multiple system atrophy (MSA), and Charcot Marie Tooth Disease (CMT). These conditions were chosen because they have been under-researched, and because of their varying epidemiology, aetiology, and prognosis (Hoppitt et al, 2011). MND is a progressive neurodegenerative disorder, and damage is to the motor neurones in the spine and brain stem. It affects motor control, is difficult to diagnose and has a rapid

degeneration, with no available treatment. It has an incidence of 3.5 (per 100,000 person years), a prevalence of 10.1 (per 100,000) and a median survival of 3.9 years from diagnosis (Hoppitt et al, 2011). Symptoms of MND include loss of voluntary movement, including speech and swallowing. O'Brien (2004) explored the information needs of service users with MND and found that they varied between people actively seeking information to people not wanting to know the longer term prognosis for the condition(O'Brien et al. 2012). If similar patterns exist for BME service users, they could be deprived of information if it is not presented in the correct format or if it is not communicated in the correct way. Huntington's disease (HD) is a neurodegenerative disorder of the central nervous system that is hereditary, and therefore easier to diagnose than conditions such as MND, but only if there is a known family history of it. The gene causes damage to the basal ganglia and the cerebral cortex that causes physical and psychological impairments. The most common physical impairment is uncoordinated involuntary movements, and psychological impairments include depression and memory impairments. Incidence of HD is 0.8 (per 100,000 person years) and a prevalence of 6.5 (per 100,000). Because of its hereditary nature, there could be great stigma attached to being diagnosed and treated for it (Wexler 2010). Soltysiak et al (2008) found that carers of service users with HD expressed difficulty in accessing respite care, and felt unsupported by health and social care professionals(Soltysiak et al. 2008). This suggests that barriers to care already exist for HD service users, and that BME service users could face additional barriers to care. Similarly, Charcot Marie Tooth disease (CMT) is also a hereditary condition but affects the peripheral nervous system. Symptoms of CMT include sensory loss in lower limbs, and muscle atrophy

that can impair walking. Sufferers can also experience muscle cramps and pain. There is an incidence of 2.2 (per 100,000 person years) and a prevalence of 12.0 (per 100,000). Post-polio syndrome (PPS) occurs only in people that have had polio, although not all polio sufferers will get post-polio syndrome. Symptoms of PPS include muscle atrophy, pain, reduced lung function and fatigue. Incidence and prevalence rates for PPS were not possible to estimate by Hoppitt et al (2011) but they did report that PPS affected 20-85% of people that had recovered from an attack of poliomyelitis. Physiotherapy for post-polio syndrome should be commenced quickly so that service users do not under or over-use the affected limb (Gonzalez et al. 2010). Multiple system atrophy (MSA) is a Parkinsonism condition that affects cells in the basal ganglia, cerebellum and brain stem and is often misdiagnosed as Parkinson's disease. It has an incidence of 0.5 (per 100,000 person years) and a prevalence of 1.2 (per 100,000). A definitive diagnosis of MSA is only possible post-mortem, and symptoms include lack of coordination, incontinence and low blood pressure.

With all of these conditions, diagnosis is difficult and if service users have the added dimension of having language difficulties, they may not be able to adequately explain the sometimes subtle symptoms that present initially, or they may not be able to convey what is happening if they believe the treatment pathway to be wrong. Equally, BME service users may be aware of symptoms, and may be fluent in English, but they may not know where to access services, or even if services exist. There is also the possibility that service users are not accessing services because the conditions

are stigmatised, and they are worried about how they will be perceived by their friends and family, or wider community.

It is therefore imperative to discover if these barriers and facilitators to care exist for BME service users with these rare neurodegenerative conditions, so that health and social care services can respond appropriately and devise ways to improve access. Equally, it would be helpful to identify facilitators to care, so that health and social care services can implement services that service users and carers will use without worry or fear.

1.2 Aims and objectives

The aim of this study was to identify the barriers and facilitators to health and social care that are experienced by BME service users with rare neurodegenerative conditions (Motor neurone disease, Huntington's disease, post-polio syndrome, multiple system atrophy and Charcot Marie Tooth disease).

The objectives of the study were:

1. To identify the route to primary care, and the reasons for presenting there
2. To see whether service users were immediately referred to secondary care, or not, and the perceived reasons for this.
3. To find out how long it took to be diagnosed
4. To identify what health and social care, and voluntary sector services had been accessed by the service users and carers
5. To identify any difficulties with accessing health and social care services

6. To identify what helped service users and carers to access health and social care services
7. To identify any factors that made service users reluctant to access health and social care services.
8. To identify what informal support was available to service users and carers

1.3 Study design and methodology

In this study, data were collected from a number of BME service users with rare neurodegenerative conditions and their carers through semi-structured interviews. Specifically, the neurodegenerative conditions of interest were motor neurone disease (MND), Huntington's disease (HD), post-polio syndrome (PPS), multiple system atrophy (MSA), and Charcot Marie Tooth disease (CMT). A variety of recruitment methods were employed because there was evidence in the literature to suggest that BME service users do not respond to traditional recruitment methods and may be considered 'hard to reach' in this respect (Hussain–Gambles et al. 2004;Mohammadi et al. 2008;Sheikh et al. 2009). The interviews were recorded and transcribed verbatim. For interviews where more than one language was spoken, a bilingual researcher checked for accuracy of the translation. Thematic content analysis was chosen as the method of data analysis (Ritchie and Lewis 2003).

1.4 Overview of thesis structure

Chapter two of this thesis provides an overview of the relevant literature on BME access to health services for patients and carers, and highlights the evidence base with regard to the main barriers and facilitators to service access. Chapter three

describes the study methodology, followed by Chapter four, which describes the various recruitment methods that were used for the study, the reasons for exploring different methods, and how successful they were. Chapter five outlines the service user journey through the health and social care system, and demonstrates where the barriers and facilitators to care were apparent for the participants interviewed as part of the study. Finally, Chapter six discusses the results and their implications, the limitations of the study, and presents ideas for future research.

2. LITERATURE REVIEW

2.1 Search strategy

A multi-faceted approach to searching for literature was taken. First, a number of medical and health-related databases were searched. These were Medline, CINAHL, Embase, and PsychInfo.

The search terms that were used for the ethnicity search were: Black and minority ethnic, ethnic minority, ethnicity, ethnic. For health and social care services the search terms were: Healthcare, NHS care, social care, health and social care. For the specific conditions that were researched, the terms were: Motor neurone disease, Huntington's disease, Charcot Marie Tooth disease, post-polio syndrome, and multiple system atrophy. They were all searched as key words and as MeSH headings.

These three searches were combined using AND, as literature that encompassed all three was of interest. However, no results were returned suggesting that there was nothing published that discussed these long term neurological conditions in relation to health and social care and black and minority ethnic service users. Therefore, the black and minority ethnic search and the health and social care search were combined using a Boolean 'AND'. Over 26,000 results were returned using this strategy. The results were limited by English Language only, and by year (2000 to present day).

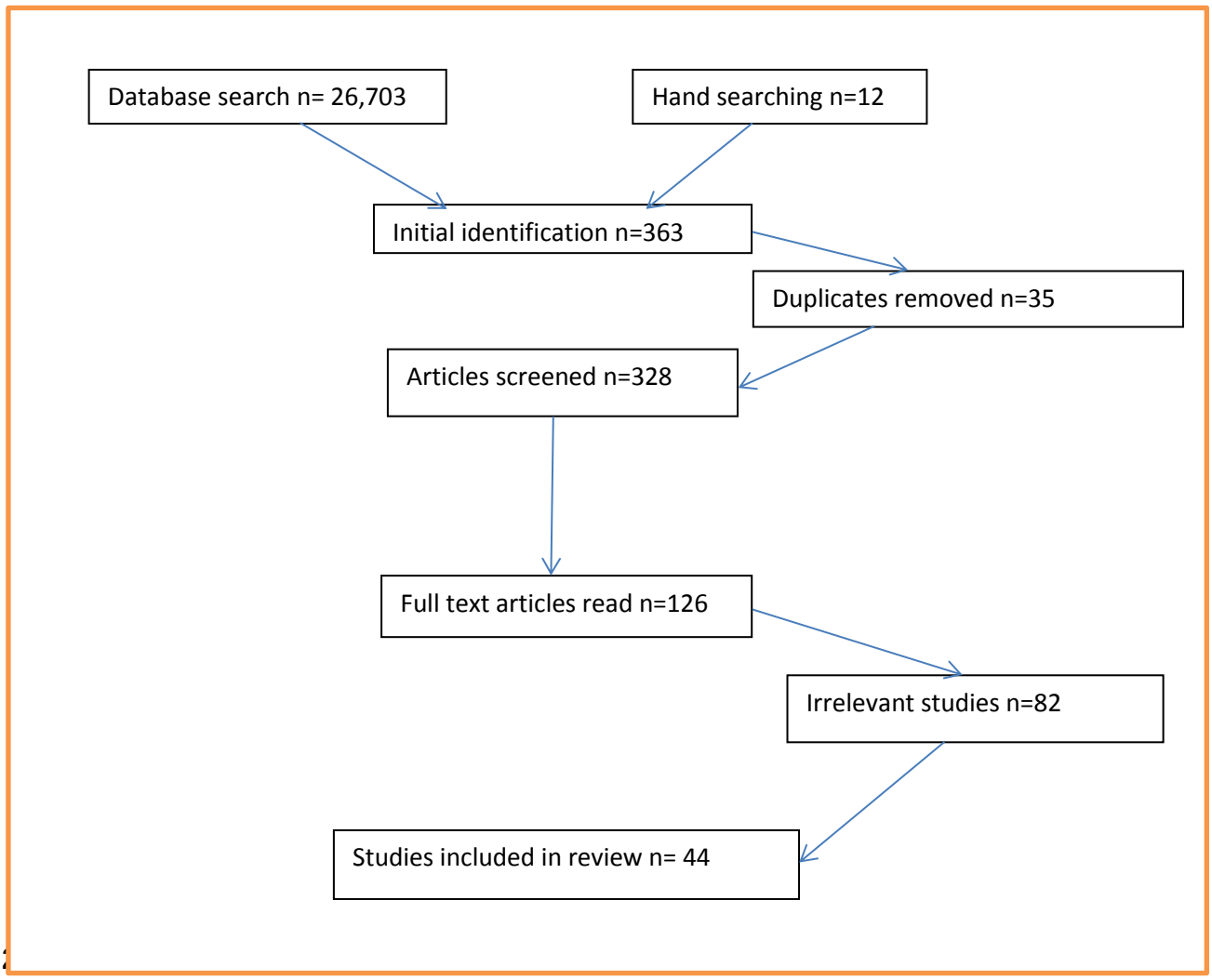
Although this was a large number of results, it was thought that it would make the search more thorough. It was important to capture all the data, so in addition to the above search, hand searching was also used. The references of papers were checked, and Google scholar was also used to find any papers that had not been identified in the original search.

Any papers that did not focus on the barriers and facilitators to access the UK health and social care system by ethnic minority groups were excluded as were those that did not describe a research study; i.e. commentaries and editorials were not included. Papers were also excluded if they didn't mention either BME groups, or health and social care as a major part of the study.

Once the literature had been identified, the papers were organised by the main themes to emerge from the literature.

The flowchart (Figure 2.1) below describes the process for the inclusion and exclusion of papers.

Figure 2.1 A flowchart showing the number of studies identified and how they were narrowed down to the final number.



This search strategy elicited 44 papers and shall be discussed below. The majority of papers that were included described qualitative studies, either semi structured interviews, or focus groups. The included studies are detailed in Appendix A which provides a summary of the authors, year of publication, the objective of the study, the participants, and the main findings. Many of the studies have focussed on South

Asians, but as can be seen from the table, other ethnicities have also been researched.

Formal data extraction was not performed as many of the studies were qualitative in nature and it was thought that it would be more interesting to consider the thematic areas that arose.

The main barriers to care that were identified in the literature were language, knowledge and awareness of services, cultural factors, and stigma. The majority of studies only included the service user and carer perspective, but some studies focussed on the health professional perspective. These studies highlighted training needs, and perceived difficulties of working with BME service users and carers.

2.3 Language

Language was identified as a major barrier to care in the majority of the studies identified. 29 studies mentioned that language was a barrier to care in a variety of contexts.

Gill et al (2009) undertook a cross-sectional analysis of the Health Survey for England and estimated that 300,000 people could not speak English, and identified a need for interpreting services to be available in primary care(Gill et al. 2009). Some studies identified that family and friends were used for interpreting (Doshani, Pitchforth, Mayne, & Tincello 2007;Free et al. 2003;Gerrish et al. 2004;Katbamna et al. 2004;Merrell et al. 2006;Owens and Randhawa 2004;Pattenden et al. 2007). Not all of these studies reported this in a negative context, however. For example, Free et

al (2003) highlighted that young people willingly did interpreting for family members. However, they did highlight where this became problematic; the nature of the health condition, and the communication skills of either the young person interpreting, or the communication skills of the health professional. Owens and Randhawa (2004) reported from a health professional perspective and found that their study sample preferred to use family and friends for interpreting, although this was in relation to providing palliative care.

Lawton et al (2006) found that their study participants did not like to use interpreters, and would have preferred bilingual staff instead. The worry about confidentiality, and interpreters who came from the same community was also highlighted as an issue for using independent interpreters (Doshani, Pitchforth, Mayne, & Tincello 2007;Lanceley and Cox 2007;Richardson et al. 102). This was especially true for conditions and illnesses that were viewed as embarrassing. Doshani et al (2007) reported that Asian women who had continence issues preferred to use a family member or friend for interpreting because of the worry that they would see their interpreter on social occasions.

Using family and friends as interpreters was not always convenient, and sometimes led to incorrect information being passed on, or worse still, information being withheld from the service user. Karim et al (2000) interviewed GPs and consultants in relation to palliative care and reported that doctors were aware that family did not always disclose the diagnosis to the service user and so palliative care was not an option. Doctors felt that using family members as interpreters was problematic and that

doctors did not believe that service users were clear about what was being said to them (Karim et al. 2000).

However, with such diverse languages, it would be difficult to employ staff to cover all languages and ethnicities. Greenhalgh et al (2007) stated that GP practices in London were employing more bilingual staff to tackle the issues that have been described above (Greenhalgh et al. 2007). Conversely, Lanceley and Cox (2007) found that some service users and carers did not like bilingual GPs, especially if they were from the same community as they were worried about confidentiality.

Language was not only a barrier to care when it came to interpreting services. It was also raised as a barrier to understanding the information that was provided (Alam et al. 2012;Manthorpe et al. 2009;Merrell, Kinsella, Murphy, Philpin, & Ali 2006;Richardson, Thomas, & Richardson 102). These studies highlighted literacy as a problem, and service users were unable to read the information that was given to them.

One study raised the issue of contacting GPs by telephone (Pattenden et al, 2007), who found that service users would wait until an English-speaking relative was available to book an appointment with their GP.

Therefore, language is a big barrier to care, and even though services have tried to tackle it by using interpreting services and employing bilingual GPs, this is not always a solution, especially if illnesses are stigmatising in any way.

2.4 Information awareness and knowledge of services

Information awareness and knowledge of services was identified as a barrier to care in 21 studies. Some of the studies raised information awareness and knowledge of services as a barrier to care because of language and literacy in some instances (Alam, Speed, & Beaver 2012;Bywaters et al. 2003;Manthorpe, Iliffe, Moriarty, Cornes, Clough, Bright, & Rapaport 2009;Ochieng 2013;Worth et al. 2009).

A few studies reported that service users valued, or would have valued information provided through education and at community events (Doshani, Pitchforth, Mayne, & Tincello 2007;Merrell, Kinsella, Murphy, Philpin, & Ali 2006;Randhawa & Owens 2004;Thomas et al. 2009).

One study evaluated an advocacy service and found that service users still struggled with information awareness despite having an advocate (Bywaters et al, 2003). This suggests that providing an advocate leads to dependence on an advocate, and does not arm service users and carers with information to access services, but provides support to access the service instead.

However, lack of the right type of information was not the only barrier to information awareness and knowledge of services. Cultural beliefs, or beliefs about certain illnesses, and how they should be managed were also barriers to knowledge of services. Randhawa and Owens (2004) found that South Asians believed cancer to be incurable, but this was because it was often too late by the time service users were referred to appropriate services. It could also mean that service users may not

have accessed services earlier, believing that nothing could be done. Turner et al (2005) found that South Asians considered dementia to be part of the ageing process and therefore were unaware that specific services were available (Turner, Christie, & Haworth 2005). St John (2004) reported similar findings, and from a GP perspective too.

Lanceley and Cox (2007) highlighted that service users were unaware of what services were available to them. One of their service users said that they would have to ask and then they would be told, but this would be difficult if you didn't know what to ask for in the first place.

Therefore, lack of information and awareness of services does have some overlap with language difficulties. It's not the only reason that service users and carers did not know about services, and it seems that some service users are responsive to targeted education and health promotion activities.

2.5 Culture and stigma

Many of the identified studies reported that cultural factors and stigma were barriers to accessing health and social care (Bandesha and Litva 2005;Bowes and Wilkinson 2003;Bywaters, Ali, Fazil, Wallace, & Singh 2003;Croot et al. 2008;de Carvalho Leite et al. 2011;Elkan, Avis, Cox, Wilson, Patel, Miller, Deepak, Edwards, Staniszewska, & Kai 2007;John 2004;Kai et al. 2007;Katbamna, Ahmad, Bhakta, Baker, & Parker 2004;Lanceley & Cox 2007;Mackenzie 2006;Merrell et al. 2005;Moffatt & Mackintosh

2009;Thomas et al. 2005;Worth, Irshad, Bhopal, Brown, Lawton, Grant, Murray, Kendall, Adam, Gardee, & Sheikh 2009).

Stigma was mentioned in a number of studies, in relation to beliefs about the causes of illnesses and disability (Bywaters, Ali, Fazil, Wallace, & Singh 2003;Chauhan, Baker, Lester, & Edwards 2010;Croot, Grant, Cooper, & Mathers 2008;John 2004;Mackenzie 2006), and in relation to acceptability of services (de Carvalho Leite, de, Killett, Kale, Nacul, McArthur, Hong, O'Driscoll, Pheby, Campion, Lacerda, & Poland 2011;John 2004;Katbamna, Ahmad, Bhakta, Baker, & Parker 2004;Mackenzie 2006;Merrell, Kinsella, Murphy, Philpin, & Ali 2006;Moffatt & Mackintosh 2009;Worth, Irshad, Bhopal, Brown, Lawton, Grant, Murray, Kendall, Adam, Gardee, & Sheikh 2009). Mackenzie (2006) interviewed Eastern European and South Asian carers of people with dementia to identify what their support needs were. They found that dementia was stigmatised in both these groups, although they had different reasons behind it. The Eastern European carers wanted to keep the diagnosis within the family because they were worried about what the community would think. They believed the dementia to be a result of war. The South Asian carers viewed dementia as a mental illness, but the stigma was associated with religion, believing the dementia to be karma. They wanted to conceal the diagnosis because they believed it would bring dishonour on the family and that it would disrupt the marriage prospects of family members.

Stigma was also mentioned as a barrier to care in receiving help outside of the family. Worth et al (2009) interviewed Muslims and Sikhs with life limiting illness in

Scotland and found that there was community stigma attached to receiving outside help. Katbamna et al (2004) explored the needs of South Asian carers in their study and found that female carers, normally daughter-in-law were prevented from seeking outside help, and even if help was offered, they would have been unable to accept it. So even if there are carers within families who would like outside help, they are prevented from receiving it because of what people might think in the wider community. Sin (2005) interviewed White British and South Asian older people to identify and understand their social networks. When asked about who should be responsible for care, the majority of the White British older adults said that the state was responsible and the majority of the South Asian older adults believed the family to be responsible for care. This also led to lower levels of awareness of what services were available, and a lower level of usage of these services. Education and targeted health promotion may have made these services more acceptable to service users and carers, especially health promotion strategies to explain the causes of illness, in order to reduce the stigma associated with them. One review paper (Toni-Uebari and Inusa 2009) highlighted the role that religious leaders could play in reducing stigma and therefore make some services more accessible.

Stigma was not the only factor that made services unacceptable to service users, however. Some studies reported that some services were perceived as culturally unacceptable and in some instances, fears that services would not fit with religious practices.

For example, Bywaters et al (2003) reported that the carers in their study did not make use of respite services because it did not fit with how they wanted to use the respite services. Bowes and Wilkinson (2003) found that their service users and carers believed residential care to be unacceptable, and that it did not meet the needs of South Asian people.

So the literature notes a clear reluctance to take up services based not only on stigma but also because services may be perceived as culturally insensitive or unacceptable.

Stereotyping by services was also problematic for accessing services and some service users perceived their colour to be a factor in how they were treated (de Carvalho et al, 2011). Owens and Randhawa (2004) interviewed health professionals working in palliative care and found that these health professionals believed Asians to 'look after their own' and would therefore be reluctant to receive palliative care. Although this was a perception of health professionals, a duty to care was also found in a study by Merrell et al (2005) who interviewed Bangladeshi carers. They believed that caring was a duty, and this was based on religious and cultural factors, which then made them resistant to receiving respite care.

So it seems from the literature that health professionals may need to break down stereotypes in order to effectively provide the right kind of care, whilst being mindful that service users may need reassurance about accessing services.

2.6 Health and social care professional perspective

Health and social care professionals that were interviewed or surveyed stated a number of different opinions about why it was difficult to work with BME service users. Some health professionals believed they needed more training and that they felt unconfident working with BME service users because of this (Badger, Clarke, Pumphrey, & Clifford 2012;Bowes & Wilkinson 2003;Edge 2010;Owens & Randhawa 2004). Many health professionals cited language as an issue, and that they felt it was problematic to have family members as interpreters (Gerrish, Chau, Sobowale, & Birks 2004;Karim, Bailey, & Tunna 2000). However, health professionals interviewed by Richardson et al (2006) raised the issue of interpreters often not being available at short notice, and that if they were available, they were not confident about the accuracy of the information passed on by the interpreter to the service user. These same health professionals also highlighted the difficulties of using interpreters, stating that service users were often reluctant to use them if they were from the same community as the service user because they were concerned that the consultation would not remain confidential.

Karim et al (2000) interviewed doctors and consultants about referral to palliative care services, and they believed that hospice care would not be suitable for BME service users because the hospice was staffed by mainly White health professionals. However, the view that services are based on Western ideals was not unique to palliative care services. Terashima (2011) found this to be the views of health and social care professionals working with people with learning disabilities.

One study aimed to find out how learning disabilities services were tackling ethnic inequalities, and found that although services had employed multilingual staff, this did not increase use of services by BME service users (Caton et al, 2007). However, they also found that these services had not met their target for employing multilingual staff, suggesting that they still had far to go in trying to improve access to care for BME service users. Employing multilingual staff could potentially be problematic too. Terashima (2011) found that Asian health and social care professionals disliked working with Asian service users because they had higher expectations.

Despite the many concerns of health and social care professionals that were interviewed, there were studies that reported the importance of treating everyone as individuals, and supporting individual needs and circumstances (Badger et al, 2012, Kai et al, 2007, Worth et al, 2009).

2.7 Summary of literature review

The literature has highlighted that the main barriers to care are language, information and knowledge of services, stigma and cultural beliefs, and from a health professional perspective, further training and breaking down stereotypes.

These barriers do not operate in isolation, instead there is interplay between all of them, and when combined these can make it difficult for BME service users to access care. The literature provided perspectives from a number of minority groups, although they were primarily focussed on South Asians.

Language was raised as a barrier to care in many of the studies, and often, the service response was to use interpreting services and employing bilingual health professionals. However, some of the studies also raised the difficulties of interpreting services, and trust and confidentiality issues that service users had about using interpreters or health professionals who were from the same community as them, suggesting that stigma and cultural factors were also issues.

The literature also provided a health professional perspective and highlighted the difficulties and concerns they faced when working with BME service users. The studies where the focus was on access to cancer treatment and palliative care was where health professionals felt the least confident in working with BME service users. All health and social care requires service users to understand what is happening to them and what their choices are, but cancer treatment and palliative care are areas where there is a much greater service user focus. It requires health professionals to build a close relationship with service users so that service users can make choices that are right for them in very difficult circumstances. If health professionals and service users don't share a common language, then building up that close relationship is very difficult, and can then make health professionals doubt whether service users are clear about the decisions that they need to make.

The conditions that are the focus of this study are life shortening, and so also require health professionals to explain difficult diagnoses and treatment options that might be available to service users. It would be vital for service users to have all the information to enable them to make decisions about their care. In some instances,

the conditions could also be viewed as having stigma attached, so all the barriers to care identified in this literature review will be relevant to BME service users with these conditions.

3. METHODS

3.1 Study Design

Interviews are widely used in health services research. They involve an interviewer talking to an interviewee on a one-to-one basis and can be structured, semi structured or open ended. Structured interviews involve the interviewer asking questions that are pre-determined and in a set order, and are almost like surveys. In open-ended interviews, the interviewer does not guide the interview, but allows the conversation and topic areas to be determined by the participant. Semi-structured interviews are the most commonly used interviews in health services research because they allow the interviewer to guide the interview to the topics that will generate relevant data, whilst allowing further probing if a participant says something unexpected and interesting.

Semi structured interviews are particularly appropriate for sensitive subject areas as participants are able to discuss issues on a one-to-one basis that they may not feel able to address in another setting, such as a group (Gill et al. 2008;Yacoub and Hall 2009). This method was thought particularly suitable for this study as some of the clinical conditions may have stigma attached. However, face-to-face interviews are not always successful in achieving honesty with sensitive issues. Murray et al (2009) suggest the use of serial interviews for sensitive issues in order to help build rapport and trust between researcher and participant through repeated meetings over time(Murray et al. 2009). Although more than one interview was not possible with participants in this study, time was used before the interview commenced to try and build rapport and gain trust with participants. In addition, interviewees were reminded

throughout the interview that specific sensitive questions need not be answered if the participant felt uncomfortable in doing so. Due to the subject matter of this study, there were also practical considerations of disability and language. As MND, HD, PPS, MSA and CMT can cause varying degrees of disability, participants may only have been able to participate if the interviewer was able to visit them at a time of their choosing. Ethical considerations also needed to be taken into account as these conditions are neurodegenerative, and some participants were in the terminal stages of their condition. However, Gysels, Shipman and Higginson (2008) found that palliative care patients and their carers valued the chance to contribute to research, and interviews allow participants to express what they are feeling, so can be therapeutic (Gysels et al. 2008). Shulman-Green, McCorkle, and Bradley (2009) suggested ways to adapt interview practice in order to make terminally ill participants more comfortable during the research process. These suggestions included asking more sensitive questions at a later stage of the interview when rapport and trust between researcher and participant is more likely to have developed (Schulman-Green et al. 2009). Language may also be an issue for some participants, and an interview situation would allow more easily for a translator to be present.

For the reasons outlined above, it was decided that semi-structured interviews would be the most suitable method of data collection for this study.

3.2 Participants

The participants in this study were service users and carers with an official diagnosis of one of the following conditions:

Motor neurone disease

Huntington's disease

Charcot Marie Tooth disease

Dominantly inherited ataxia

Multiple system atrophy

Progressive supranuclear palsy

Post-polio syndrome

An official diagnosis was one given by an NHS professional, so participants were therefore known to services. The participants that were recruited through the voluntary sector provided evidence of their diagnosis (a hospital letter) after interview. The participants recruited through the disease-specific neurology clinics did not have to provide evidence of their condition as the neurologists had already identified them as having that condition. As well as having an official diagnosis of one of the above conditions, participants also had to be from an ethnic minority. For this study, the 2001 census categories for ethnicity were used to define which individuals would be classified as BME (ONS, 2001). There are 16 categories for ethnicity in the census. See table 3.1 below:

Table 3.1 A table showing the ethnic categories used by the 2001 Census.

White	White British
	White Irish
	White Other
Mixed	White and Black Caribbean
	White and Black African
	White and Asian
	Other Mixed
Asian or Asian British	Indian
	Pakistani
	Bangladeshi
	Other Asian
Black or Black British	Black Caribbean
	African
	Other Black
Chinese	
Other Ethnic Group	

Out of these 16 categories, only people who identified themselves as White British were ineligible for the study. In addition, participants had to be aged 18 and over to

participate. There were no other exclusion criteria, such as time since diagnosis and language competence, in order to include as many people as possible.

3.3 Recruitment Methods

Research suggests that barriers exist to recruiting BME participants into research, and BME participants may not respond to traditional recruitment methods (Hussain–Gambles, Atkin, & Leese 2004;Mohammadi, Jones, & Evans 2008;Sheikh, Halani, Bhopal, Netuveli, Partridge, Car, Griffiths, & Levy 2009). Therefore, a number of recruitment methods were employed in order to maximise the likelihood of recruiting sufficient individuals with the conditions of interest. They included visits to temples, a health fair, developing relationships with link workers and community leaders, an interview slot on a community radio station, contacts with disease-specific charities, and recruitment through locally based neurology clinics. For a more detailed account of the recruitment methods used and the rationale for using them, see Chapter 4.

3.4 Setting

Service users and carers could choose to be interviewed either in their own home or at the University at a time that was convenient for them. The majority opted for an interview in their own home, with only one person asking to be interviewed at the University. One person was interviewed by telephone as they lived far from the University, and because they did not have any difficulties with language or speech. The face-to-face interviews were the preferred method of interviewing as they provided a better avenue for building rapport, and facilitated the use of non-verbal cues to ensure that the participant felt relaxed during interview.

3.5 Interview Schedule Development

The interview schedule is a key component of a semi-structured interview. Asking the right questions is crucial to ensure that relevant and usable data is collected (Britten 2006;Green and Thorogood 2009). The interview schedule was initially developed following a literature review (see chapter 2). Questions related to the aims and objectives of the study, barriers to care, and cultural identity (e.g. language spoken at home, religion, and country of birth). As it was evident from the literature that individuals' level of involvement in their local community may be an important indicator of the strength of their ethnic identify, questions were also asked about community involvement which also allowed an assessment of whether or not community involvement impacted on access to healthcare services.

Salway et al (2007) found that some minority groups were more likely to access certain services if they were aware of others in the community accessing the same services, as knowing about other people in the community who had accessed some services may have removed the stigma attached to accessing them (Salway et al. 2007). A list of services was included in the interview schedule as a prompt in order to ascertain knowledge of the available services. This was to identify if participants were aware of these services, and to discover reasons for non-access.

The interview schedule was regularly reviewed so that unanticipated topics raised in earlier interviews could be formally incorporated into the schedule for later interviews.

A copy of the interview schedule can be found in Appendix B.

3.6 Data Collection

Although a pilot study was not possible for this piece of work because of funding and time constraints, analysis began after the first interview, enabling changes to be made to the interview schedule, and to add issues that may have been missed, similar to what a pilot study would have added.

3.6.1 Eligibility and Consent

Participants were recruited through various methods described (See Recruitment chapter 4). Participants were asked about the condition they had, and their ethnicity. After all questions had been answered, if participants met the eligibility criteria and if participants were satisfied with the information, they were invited to participate. It was made clear that they had the right to withdraw from the study at any point, and that they did not have to give a reason. Participants were assured that no data that they had provided would be used in the study if they wished to withdraw. At this point, an appointment was made for interview.

At the time of interview, the researcher went to the participant's home at the arranged time. The study was explained to the participant and carer if they were present. The researcher went through the information sheet in detail and answered any questions. Power differentials exist between the interviewer and participant that can also affect the interview process (Karnieli-Miller et al. 2009). They state that power can shift

between the interviewer and the participant, with the interviewer in control of the questions asked, and the participant in control of how or what they answer.

Therefore, it was important to ensure that participants understood what they were consenting to, and to be certain of what their rights were. Written consent was obtained at this point if participants still wanted to go ahead with the interview. DiCicco-Bloom and Crabtree (2006) note that there is not much time to build rapport in an interview, and suggest that interview schedules are designed so that the interviewer and participant can ease into the interview (DiCicco–Bloom and Crabtree 2006). However, the time taken to explain the interview process was equally important and enabled the participants to ask questions, and feel confident with it, which would have helped with rapport-building during interview.

As the researcher was interviewing participants alone, a lone worker policy was put in place. It was ensured that this was in place for every interview where the researcher was attending a participant's home.

To obtain consent for the telephone interview, the researcher emailed the information sheet and consent form to the participant in advance of the interview. When the participant responded to say that they wished to participate, an email was sent to ask if they had any questions about the study, or if they required further information. If they were happy to continue, they were asked to return a signed and initialled consent form and a date and time was set for interview. At the start of the telephone interview, the participant was asked again if they had any questions and if they were happy to proceed.

All service users had capacity to consent and carers that participated in the interviews were consented into the study. The carers that participated in the study also read the participant information sheet and signed the participant consent form as they were considered to be participants. If the service users had not been able to provide consent, an assent form was available to carers if they believed that participation in the study was in the best interests of the participant. The participant information sheet can be found in Appendix C, the carer information sheet in Appendix D, the participant consent form in Appendix E and the Assent form in Appendix F.

3.6.2 The Interview

The majority of interviews lasted for approximately one hour.

During the interview, the researcher asked questions to both the service user, and carer if they were present. In some interviews, the researcher did not have a shared language with the participant so questions were directed towards the carer who translated the question for the service user, and then translated their response. Where the researcher and participant do not share a common language, Green and Thorogood (2009) suggest the use of an interpreter. Although funding for interpreters was available, there was either no need for interpreters during the study, or interviewees declined to use them. This may have been because of stigma may have been an issue for some people, so it was thought that using a family member as interpreter would be better for building rapport. In addition, the focus of the interview was about services received through health and social care, so it was thought that an informal interpreter would allow the participant to express themselves fully. Although participants were given assurances of confidentiality, if an interpreter had been

present who was from the same community as the participant, they may have been less reluctant to participate in the interview. Vickers, Craig and Atkin (2012) state that using family as interpreters may result in questions being phrased differently to how the interviewer would like, but they also state that using professional interpreters could result in less rich data (Vickers et al. 2012). Occasionally, the service user would use broken English to respond, and the researcher was able to understand what they were saying, although this was always clarified with the carer. Britten (2006) highlights the importance of clarification in interviews, especially when language is not shared.

Similar procedures were followed for the two interviews that were not conducted in a participant's home. For the telephone interview, the participant had the study explained to them and were asked if it was ok to be put on speaker phone, and for the telephone call to be recorded. The researcher was in a private room and had no interruptions throughout the interview, and the participant was assured of this too.

3.7 Data Analysis

Most of the interviews were audiotaped and were transcribed verbatim. A researcher based at the University of Birmingham transcribed the interviews. Britten (2006) noted the advantages to recording an interview rather than taking notes, as much more data can be captured, and the interviewer can pay more attention to non-verbal cues when conducting the interview. Pope and Mays (1995) also advised the recording of interviews in order to improve rigour (Pope and Mays 1995). However, not all participants were comfortable with the interviews being recorded and therefore

out of the 14 interviews, notes were taken for two of them when participants requested not to be audiotaped. As the researcher did not transcribe the tapes directly, the audio file was checked against the transcript for accuracy, and to get close to the data. This is important for data analysis (Bailey 2008;Green & Thorogood 2009). As some of the interviews were conducted with participants who spoke little or no English, the transcripts only included the English translation. However, the transcripts did state when someone spoke in a different language as it was deemed important for analysis to establish whether a question was being answered by the service user or carer. In order to ascertain the reliability of translations made by carers, a researcher who was fluent in the language of some of the participants listened to the interviews against the transcript and clarified that the translation was correct and that the carers were asking the questions that were intended. Written notes were kept of interviews that were not recorded.

There are a number of approaches to qualitative data analysis. Thematic content analysis was used to analyse this set of data. This is a widely used method in health services research (Green and Thorogood, 2009). Grounded Theory (Glaser and Strauss 1967) is an inductive approach and many of the analytical methods used in thematic content analysis follow that of Grounded Theory. However, the crucial difference between thematic content analysis and Grounded Theory is the development of a theory to explain the data. Thematic content analysis can give a highly descriptive account of the data, whereas Grounded Theory requires a theoretical explanation of the data. Grounded Theory also relies on data saturation, a point at which more data cannot provide anything new to the theory. However, as this

piece of work had both time and funding constraints, it is unlikely that data saturation would have been reached.

Some themes were already expected from the data as the interview schedule included questions that were informed by existing literature. Although thematic content analysis is regarded as an inductive approach (Burnard et al. 2008), some themes were based on the literature, and other themes were new and emerged from the data. This was necessary because although a purely inductive approach would be desirable in letting the data speak for itself, specific research questions needed to be answered to fulfil the funding requirements. Therefore analysis was both inductive and deductive.

Analysis began as soon as the first interview was completed. Once transcribed, all interview data was stored using NVivo version 8 (QSR International). NVivo is a useful tool for aiding the analysis of qualitative data. It has an open coding function, which allows for emergent themes to be highlighted, and it allows for these codes to be transferred across once a more formal coding framework has been developed. It enables the researcher to see how codes may be related, and can retrieve data relating to a particular code.

This was done initially to identify emergent themes. The open coding helped to identify themes and provided a rough framework to work from. When codes were assigned to sections of the data, enough detail was selected so that the context of data could be captured. As analysis is an iterative process, the initial codes could be

tested against further interviews to check whether they had any relevance. To ensure that meaning was attached to the code, a description was written on each code. For example, ‘Language’ as a code was a little bit vague and could have had a number of meanings attached to it. Therefore, to the ‘Language’ code, the following description was attached to it:

“’Language’ refers to all instances in the interviews where people have expressed difficulties in service access due to language difficulties, explicit or implied.”

This function was also possible on NVivo. Once there was a complete set of data, all codes could be tested against the interviews, and at this point, a coding framework was formulated. Codes which did not have any relevance to the interviews, were discarded. Codes which were relevant to the dataset were incorporated into the coding framework, and codes that had similar meaning to other codes were combined. For example, codes such as ‘Language’ and ‘Knowledge of services’ were included in the over-arching theme of ‘Barriers to care’. Rigour in qualitative research is important in order to ensure that the work is replicable. One way to achieve rigour in qualitative research is by using multiple coders (Barbour, 2001, Mays and Pope, 1995). Therefore, the interviews were coded independently by two researchers (SS and QF) and emergent themes were discussed. Any discrepancies were discussed until a final coding framework was agreed. The use of more than one researcher in data analysis is recommended to improve reliability of the analysis (Pope and Mays, 1995).

Another way to achieve rigour is to ask the participants to check the accuracy of the interviews once they have been transcribed (Barbour, 2001). Once the interviews had been transcribed, they were sent to the participants if they had said that they

wanted to check them. However, as many of the service users were unwell, and the carers were busy, this was not something that many of the participants had time for. Barbour (2001) suggested that respondent validation was particularly useful in action research where service users were actively involved in the research. However, she also said that it placed a burden and demand on participants and that in some instances, may have been distressing to them. The service users that did check the transcript were able to clarify some parts of the transcript and were able to correct names of health professionals they had mentioned.

There are other methods that can be employed to ensure that rigour is achieved such as triangulation and purposive sampling (Barbour, 2001). However, it was out of the scope of this study to use triangulation, and purposive sampling was not possible with such rare conditions.

3.8 Personal Biography

A number of factors can affect the interview process, such as the interviewer's race, gender and cultural identity (Bhopal 2001).

There is evidence to suggest that ethnic matching between interviewer and interviewee may help with the interview process (Bhopal 2001;May 2011). Adamson and Donovan (2002) discuss the issue of insider and outsider status when interviewing i.e. if someone is ethnically matched, they would be said to have insider status (Adamson and Donovan 2002). However, the eligibility criteria for this study meant that all minority groups could participate, thus it would have been impossible to match interviewer to interviewee for every interview. However, I am from a minority group, and although I do not fall into the main South Asian religious groups, I am of

Indian descent, and it was thought that the main minority populations of the West Midlands would be from the Indian Sub-continent. My parents are East African Asians, and I was born in the UK and brought up as a Jain.

As this study was specifically considering the views and experiences of people from ethnic minorities, it made me consider my own feelings and experiences of being an ethnic minority person in the UK, and how this would affect participants before and during interview.

There were a number of times when I found myself having to disclose my own ethnicity to people, but this was before the interview began. One person I contacted was European, and when I explained that the study was interested in interviewing people who were not White British, she contested this. She said she was White, and she was British. She had been a British citizen for a number of years. I had to explain that I too was a British citizen, but that because of my origin, I was regarded as an ethnic minority. She accepted this explanation and said that her ethnicity was indeed White European. Disclosing my own citizenship and ethnicity was necessary for clarity of ethnicity. This did make me consider my own ethnicity. I realised that despite being born in the UK, because of my name and the colour of my skin, I would always be viewed as an Indian. Interestingly, on holiday in India, I was seen as the English girl.

With participants who described their ethnicity as British Indian, my ethnic identity helped to build rapport. Rapport building is essential for interviews (Green and Thorogood, 2009), and before interview, many participants would ask personal

questions, including where I was from, where my family were from, whether I was married. At the time of interview, I expected these questions and felt comfortable answering them. Although some of the conditions did have stigma attached (Huntington's in particular), the participants from a South Asian background felt comfortable enough to speak to me. Song and Parker (1995) spoke about commonality and difference with their identity in relation to their interviewees and how this sometimes led to more disclosure in interview (Song and Parker 1995). As I was seen as being of Indian descent, but not in the main religious groups, or even from the local area, the participants may have felt able to speak more freely in interview. Coleman-Bruekheimer, Spitzer, and Koffman (2009) interviewed people from a particular Jewish community and found that it was helpful to be from a different Jewish community as there was enough commonality for there to be a shared understanding, but there was enough difference to ensure that confidentiality would be maintained so that sensitive information could be disclosed (Coleman-Brueckheimer et al. 2009).

Song and Parker (1995) and Bhopal (2001) highlight that in interview people can include the interviewer in a collective 'we'. That is to say, a participant may speak about something to do with their ethnicity and include the researcher in that. This did not happen to me during interview and therefore makes me consider whether I was seen as an insider. The only indication that I may have had knowledge of an Indian community was when one participant said "you know what Asians are like, they can be nosey". Egharevba (2001) wrote about her experiences as a Black researcher interviewing South Asian women. She noted that although she was from a different

ethnic group, some of her participants were able to speak about sensitive subjects such as race that they wouldn't have been able to discuss with a White researcher (Egharevba 2001). There were two cases where participants explicitly brought up racism, and I wonder if they would have felt comfortable bringing up these topics had I been White.

Although I am a British Indian, I do not speak Hindi. Instead I speak Gujarati, and I felt embarrassed about not having a shared language with some of the British Indians. Speaking Hindi would have helped me to communicate with the British Pakistanis too, as there are similarities between the Hindi and Urdu languages. Prior to interview, some of the British Indians did ask me what language I spoke, and whether I spoke Hindi. I don't know how this knowledge would have altered their perception of me, but I may have been seen as different enough for them to trust me during the interview, or not similar enough.

Religious identity was another factor that may have helped when interviewing the South Asian participants in particular. Whilst I am not a practising Jain, when participants enquired about my religious identity, I simply said that I was brought up as a Jain, or that my parents were Jain. Being outside of the main South Asian religions (Hinduism, Sikhism and Islam) may have helped to maintain neutrality as Jainism was similar enough to warrant inclusion and trust. I felt unable to say that I did not follow a religion because I felt that would have been unacceptable to many of the participants. Saying that I was brought up as a Jain would have alerted the

participants to the values and principles that I was brought up with and they may have identified similar values and principles as a result of that knowledge.

There were two participants who spoke Gujarati, although one participant mostly spoke in English. With this participant, communication felt easier, and the interview seemed to flow more. As we both spoke English and Gujarati, this person was able to speak to me in both languages interchangeably during interview. As this is how I speak to my parents, this felt perfectly normal to switch languages, and may have led to a fuller interview.

Whilst I felt comfortable disclosing personal questions about myself in order to build rapport, I did not expect to feel the way I did during and after the interview. A lone worker policy was in place to ensure my safety when I was interviewing participants in their own home. However, I did not consider the psychological impact that the interviews would have on me. As I had considerable experience of working in mental health, and experience of interviewing many different participants for qualitative research, I thought that I was well prepared to interview this set of service users. Much thought had been given to the capacity of service users to consent, and ensuring that they did not need to answer questions that they were not comfortable with. Bahn and Weatherill (2013) reported that sometimes interviews needed to be cancelled if the health status of an interviewee had changed between confirming the interview in the morning, to feeling to unwell to participate in the afternoon. Whilst this did not happen to me when I interviewed participants, I did notice that some questions had been difficult to answer for some service users, so I made a decision

not to continue with certain lines of questioning. This was especially true for some lifestyle changes questions, and questions about end of life care.

However, I was unprepared for how I would react to these participants' stories, and to their circumstances. The same similarities that may have helped to build rapport also made me feel somehow closer to these participants and therefore the knowledge that some of these service users were terminally ill made the interview difficult to conduct. As I was an experienced qualitative researcher, I did not consider the need for supervision and de-briefing. Dickson-Swift et al (2008) and Bahn and Weatherill (2013) both suggest the need for professional supervision where sensitive issues are discussed in order to protect the researcher. Although supervision was an accepted part of practice in my mental health work, I had not considered this at all in this situation. Protection of the participant is of great importance and whilst that will always be true of any research, it is worth considering the impact of the research on the researcher. Experience should not be a factor when considering the needs of the researcher, but careful timetabling of supervision would be helpful if the researcher needed extra support. No researcher can determine prior to any interviews how they will react to different situations, and it is possible that the personal history of the researcher could impact on how they will react, whether they are aware of it or not. Further work needs to to explore the impact of research on the researcher, and on strategies that would provide greater protection to both the participant and the researcher.

3.9 Ethics

A favourable ethical opinion was given by North Staffordshire Research Ethics Committee (Ref: 08/H1204/184) in July 2009 (please see Appendix G for a copy of the Ethics letter). Permission was sought from this committee as they have specialist expertise in research undertaken with vulnerable adults and in cases where there may be mental capacity issues. Fovargue and Miola (2010) highlight the rules governing research with adults who do not have capacity to consent and which regulations need to be followed (Fovargue and Miola 2010). They state that as a non-clinical study, the Mental Capacity Act 2005 (Great Britain Parliament 2005)would have applied for this study. However, as ethics permission was sought from the National Research Ethics Service (NRES), the Medicines for Human Use (Clinical Trials) Regulations 2004 also applied. Therefore, when seeking ethical permission from NRES, a strong case for recruiting participants who had mental capacity issues was put forward. The Mental Capacity Act 2005 (MCA) has specific rules about researching people who lack mental capacity. The MCA states that if research is conducted on people who lack capacity, then it has to be relevant to their condition and that the research will benefit other people who have that condition. In common with all research that involves NHS patients, the research must not cause any harm to the participant. If family members or carers are providing assent, then they must be certain that the participant would have consented to participate themselves, and there must always be the option to withdraw from the study. It was thought that some questions in the interview schedule may cause distress, but it was made clear to all participants that they did not have to answer questions that were distressing and that they could stop the interview at any stage. This was particularly

important in instances where participants were unable to directly consent to participate in the study, but carers or family members were providing assent. However, all service users had capacity to consent at the time of the interview, and no carers or family members provided assent.

4. RECRUITMENT METHODS

4.1 Introduction

As noted in chapter 3, Black and Minority Ethnic (BME) populations still appear to be under-represented in health services research. Due to the rare nature of the conditions investigated in this study, it was anticipated that the number of BME service-users eligible for participation would be small. Previous studies indicate a prevalence of between 3 to 10 cases per 100,000 of the general population (Hoppitt et al. 2010). Prevalence within the BME population of the UK is unknown. However, BME only accounts for 14% of the UK population (Census, 2011) and assuming prevalence rates are comparable, the number of BME service users in the UK will be low. Consequently, it was decided that interviews with BME service users would be conducted in order to provide in-depth data on a small sample of people.

Historically, people in the BME community were perceived as ‘hard to reach’ and the low representation of BME groups in research was attributed to this. A thematic review of clinical trials revealed a number of factors for low BME representation in clinical trials. Factors included language barriers, cost, health provider attitudes, and suggestions that BME participants may not understand research (Hussain-Gambles, Atkin, & Leese, 2004). Sheikh et al (2009) interviewed researchers and community leaders based in the UK and the US and identified a number of strategies that would help to improve recruitment. They suggested that researcher attitudes would make a difference to participation. For example, they found researchers sometimes held stereotypical views about BME communities, and that they perceived BME communities as difficult to engage. In addition, they found that community leaders

had little knowledge about research and its aims (Sheikh et al., 2009). These findings suggest that, in order to increase research participation and awareness, researchers need to build relationships with their local BME communities, and educate local community leaders about the rationale behind their research. Mohammadi et al (2008) suggest that multiple recruitment strategies need to be used in order to maximise recruitment. They used a number of different strategies in their own research, including snowball sampling and advertising. Douglas et al (2011) used a multi-pronged approach to recruitment into a diabetes trial, and found that traditional methods, for example, recruitment via GP surgeries, had limited success. Snowball sampling and building relationships with local BME organisations were the most effective methods of recruitment (Douglas et al. 2011).

In an attempt to maximise recruitment of BME service users to participate in a one-to-one interview regarding their experiences of health and social care services, a number of different recruitment methods were employed, focusing particularly on methods that had been successfully used in previous studies.

4.2 Methods

Recruitment strategies ranged from more traditional approaches, such as recruitment through clinics in the NHS, to more alternative methods, such as visiting temples and attending community events.

4.2.1 The interviewer

The interviewer in qualitative research plays an important role in obtaining accurate and complete information from an interviewee (Holloway and Wheeler 2002). The interviewer's background and ethnicity may have impacted on both recruitment and on data collection, so this shall be described in more detail. I am a British born East African Asian; my parents came to the UK in the early seventies because there was trouble in East Africa, and although they hadn't been directly affected (they were in Kenya), they made a decision to leave. It was something that wasn't really spoken about when I was young, and they consider London to be their home. I was brought up in London and because I have three older sisters, I spoke mostly English, and sometimes Gujarati at home and at school I spoke only English. I was brought up as a Jain, a religion that is less well known, but most people from the Indian sub-continent would be aware of it. I do not conform to any religion as an adult, and I only occasionally go to family events. As I live away from my family and the wider community, I would say that my experiences are apart from other Asians who are more involved with their own communities. I have enough knowledge of my own community to create a belief that there is a similarity, but I am removed enough so that people are able to disclose very personal information.

A number of studies have considered power differentials that may play a role, and may therefore have an impact on the type and quality of interview data that is collected. For example Carter (2004) described potential difficulties encountered when he, as a White male researcher, interviewed African Caribbean nurses about issues relating to work and ethnicity (Carter 2004). I was responsible for engaging with and recruiting participants from the BME community, and although I am of Indian

origin, I do not fall into the main religious groups of Hindu, Sikh or Muslim. Grewal and Ritchie (2006) state that a shared language and ethnicity is helpful for data collection in a qualitative interview (Grewal and Ritchie 2006). However, Coleman-Bruekheimer, Spitzer, and Koffman (2009) interviewed people who were from a similar community of Jews, but not from the same community as the interviewer. They stated that this may have helped because the participants would have believed the interviewer to have a shared understanding of their culture, but would also have been able to discuss more sensitive issues that they may not have divulged had the interviewer been from the same community. Therefore, not falling into the main religious categories may have been beneficial, so consequently, I was keen to immerse myself in other cultures in order to build rapport with local communities.

4.2.2 Temple visits

It was thought that visiting temples would be a good way to engage with different BME communities and provide an opportunity to meet with community leaders. It was thought that community leaders may act as gatekeepers to potential participants, so gaining their trust would help with recruiting participants into the study. Rooney et al (2011) explored the barriers and facilitators of recruiting South Asian participants into an asthma trial. They found that participants were more likely to participate in research if a trusted member of the community recommended it. They suggested that it would be helpful for researchers to build trust with members of the community to increase participation (Rooney et al. 2011). However, as potential gatekeepers, it is also important that community leaders understand the research so that they are in a position to recommend it. One study found that community leaders had difficulty

understanding the importance of research, especially BME research, and therefore needed educating (Sheikh et al., 2009). Another study found that they achieved a high participation rate from African Americans when researchers were trained in the appropriate ways to approach people (Thompson et al. 1996). These studies suggest understanding prospective participants may influence recruitment rates. In order to build familiarity with local communities and break down cultural barriers, a number of visits were made to temples in the West Midlands area in order to build relationships with community leaders and members of the community. This geographical area was convenient due to both its proximity to the University of Birmingham, and ethnic diversity. The majority of the conditions of interest to this study affect adults in middle to old age, so visits were made during weekdays when the temples were attended by older community members who were retired. An initial visit to a Hindu temple allowed the opportunity to observe the kinds of activities people were involved with, and acted as a learning experience for how I, as a British Indian female, should behave in that environment. As I was a new face in the community, people were interested to know who I was and what the purpose of the visit was. Egharevba (2001) stated from her own experience how offering information about oneself helped to build rapport and break down any hierarchies. Therefore, I offered information about myself such as where I was from and information about my family. I also spoke to people in both English and in Gujarati. Community members reciprocated and were keen to learn more about the study. Many of them had not heard of any of the conditions although they did share details of health conditions they and members of their family had. However, I was given the opportunity to explain in more detail the kinds of conditions and common symptoms. These repeated visits resulted in building relationships with

members of the community and community leaders. Community leaders at key Hindu and Sikh temples agreed to try and identify people within the community, and I continued to integrate with community members. On one occasion, I was asked to speak to the whole group and explain what the study was about, how it was beneficial, and that I would be willing to make home visits. Study leaflets available in English and Gujarati were also left at the temples. Unfortunately, despite a great deal of interest in the study by many community members, no-one who attended these temples had, nor were aware of anyone with the conditions. Building these relationships and learning how to behave in these communities was helpful for when I recruited and interviewed participants. It enabled me to behave appropriately, and it may have helped to build rapport with participants.

4.2.3 Health fair

A stall was set up at a health event in a temple organised by a large Hindu temple in collaboration with Sandwell PCT. A similar event that was held in a mosque, where all attendants were able to have their blood pressure measured, was well received and people took an interest in their health (Ghouri 2005). Our study leaflets were available in English and Gujarati and it was anticipated people would pick up a leaflet and pass it on if they knew anyone with the conditions. However, this did not result in any participant recruitment, possibly due to the rarity of the conditions, and the lack of awareness and interest in the conditions.

4.2.4 BME health link workers

The Health Equality Act (2010) requires all public services to be equally accessible to all. As a result, many NHS trusts have policies in place to monitor ethnicity data and have developed strategies to overcome inequalities. As part of this strategy, Sandwell PCT employed link workers whose role was to develop links with BME service users, and to promote health to specific BME service user groups. The main objective of their role was to raise awareness about health issues that may affect minority groups and to provide information about the types of services that were available. It was hoped that they would come into contact with people with the conditions being investigated in this study by attending community events and promoting well-being classes. It was thought that the link workers would already be known to the communities they were targeting and would act as go-betweens to recruit participants. Bhopal (2010) found this to be the case when trying to recruit Gypsy families into research. She used the Traveller Education Service (TES) to access Gypsy families for research. As Gypsy families placed a great deal of trust in the TES, with their recommendation, participants were recruited into the study (Bhopal 2010). Although the link workers were interested in the research and wanted to help, no one with these conditions was identified.

4.2.5 Media

The study received a 45-minute slot on a community radio station in an information-specific programme. The aim of the show is to inform listeners of any changes to the health services, and to encourage people to get involved in health consultations. This particular programme is listened to widely in the Muslim community and it was

thought that it would reach a wider variety of people not visible in other areas of the community. It was thought that a radio slot would offer an alternative to only having written materials to promote the study, and that it would attract people who understood a different language but could not read or write in that language. The programme was conducted in both English and Urdu. I was interviewed by the regular radio presenter and explained what the conditions were and the kinds of symptoms that people may experience. This was done because some people may have been unaware of their own diagnosis. Although there is no evidence to suggest that diagnoses of these neurological conditions are concealed from those with them, there may have been cases where people knew their condition by a different name, but may have recognised the symptoms. However, the programme did not result in any contacts or enquiries.

Although previous studies had reported that newspaper advertisements were ineffective (Mohammadi et al 2008), newspapers targeting Asian and the Black communities were contacted. Despite emailing and writing to editors or health editors, the study was not featured, and consequently this strategy was unsuccessful in recruiting any participants.

4.2.6 Snowball sampling

Snowball sampling can be a useful strategy with hidden or hard to reach populations. It has been used to investigate drug use, sexuality, and HIV (Browne 2005;Carlson et al. 1994;Ekstrand et al. 1999). Snowball sampling is particularly useful where the characteristics being researched (such as drug use) have a stigma attached and it is

effective if participants are in a network with the common interest is the item of research interest (Faugier and Sargeant 1997). Bhopal (2010) found snowball sampling to be effective when there was a low response to other forms of recruitment. It was therefore thought that snowball sampling may be effective in recruiting service users into this study. However, participants with genetic conditions did not know or pass on study details to other people. This may have been due to the stigma attached to these conditions, and may also have been to respect the privacy of others with the condition. In addition, participants also tended to withdraw from any social activities and were reluctant to use any respite or day centre resources. They therefore did not come into contact with other people who had the same condition as them. This combined with the rarity of the conditions meant that snowball sampling was ineffective.

4.2.7 Voluntary and community sector

Condition-specific charities and locally based BME charities were contacted about the study. The locally based BME charities that were contacted were quite unresponsive despite repeated requests for help. They cited that they did not have time to help with research, but this also meant that as gate-keepers to potential participants, there was a group of people we would not be able to access. Rugkasa and Canwin (2010) highlighted how they also had similar problems when recruiting participants into their study, with some organisations stating that they would not undertake research for ‘free’ (Rugkasa and Canvin 2011). The charities contacted in this study did not request payment, however they appeared to lose interest as soon

as the conditions were mentioned, suggesting that they may not have come across anyone with those conditions.

Condition-specific charities raised awareness of the study. The charities had study information and contact details on their websites, sometimes on the front page, and they also had details of the study in their newsletters. One charity had a register of members who were notified of research, and each member was approached by email or letter informing them of the study. This generated a great deal of interest, with many people enquiring about the study. Two different approaches were used to recruit BME participants specifically. Name searching has been successfully used in other areas of research. For example, Hughes, Fenton and Hine (1995) used the Electoral Register to identify participants from a BME background (Hughes et al. 1995). This study was part of a wider research project, which also involved participation in a survey that included White British participants. Therefore, people who enquired to take part in the survey whose name did not appear to be typically White British, were asked directly to confirm their ethnicity. In situations where these participants were not White British, they were invited to participate in an interview. This resulted in five interviews. This was one third of all interviews conducted so although it was a successful approach, it may have missed people whose names were not obviously from an ethnic minority.

To try and minimise this, where it was not clear if participants were White British, an email was sent specifically detailing the option of interview if someone was in a different ethnic group from White British. This did not result in any interviews. Some

people did question (by email) the reasons for interviewing BME and not White British service users. Some people felt that this was unfair as they would not be able to share their experiences of services in as much detail as people from an ethnic minority group. However, individual and a blanket email response explaining the reasons for interviewing BME service users were sent. The reasons given were that people from BME backgrounds may have been less likely to respond to a survey, making any data less meaningful, and that the funding body had specifically requested that this was done. A number of these people replied thanking me for the explanation and confirmed understanding of the strategy.

4.2.8 Neurology and condition-specific clinics

In addition to more alternative approaches to recruitment, a more traditional method of recruiting through the NHS was also thought to be an important strategy. Neurologists based in Birmingham, and who specialise in some of the conditions of interest helped to recruit participants into the study. A research nurse sat in neurology clinics and neurologists sent suitable participants to the research nurse. The research nurse explained what the study was about in more detail and offered an information sheet. If participants were interested in the study they were given details of a researcher whom they could contact to ask more questions about the study, and to arrange an interview. In a separate neurology clinic, the neurologist gave a study information sheet to the service user and their carers when they attended clinic, explaining what the study was about, and to get in touch with the contact person on the information sheet if they were interested in participating. This

was the most successful strategy in recruiting BME participants into the study and resulted in ten interviews.

4.3 Discussion

The most successful strategy for recruiting BME participants was recruiting through neurology clinics. Consent rates were high for this method of recruitment and suggest that BME service users with these conditions are willing and interested in participating in research. This finding was surprising as other studies had found recruitment through health services difficult (Douglas et al, 2011). However, this finding is consistent with Wendler et al (2006) who looked at all trials that reported invitation rates and consent rates for BME. They found that consent rates into studies was slightly higher in the BME population, and that figures were low because fewer BME people were invited to participate in research (Wendler et al. 2005). Rooney et al (2011) also found that their participants had not previously been approached to participate in research, although perhaps the recruitment methods used by researchers contributed to this. There may have been a number of reasons for this success. Firstly, the health professionals themselves had a keen interest in the research and were willing to dedicate time to it. Secondly, the nature of the research may have made a difference to recruitment. This study required participants to do a one-off interview at a time that was convenient for them, usually in their own home. In contrast, involvement in a clinical trial may require involvement over several years, may involve a number of tests, possibly taking new medication, which may put off a number of people. Thirdly, as the conditions are rare, and in some instances, life limiting, people may have been more responsive to participate in research. Some

people did say that they wanted to do whatever they could to help others in the future.

The response from the voluntary and community sector was surprising as it was anticipated that people from the BME community would be less likely to use these services. That is also why non-condition specific BME charities were also contacted. Contacting the non-specific BME charities did not help with recruitment. Possible reasons for this could be time and financial pressures on the charities. Nevertheless, charities increasingly work closely with health and social care to provide a complete package of care. As early as 2004, a strategic agreement between the voluntary sector and the NHS was developed so that charities would be providing services alongside the NHS to enhance service provision and patient choice (DH, 2004). This may explain why the condition-specific charities yielded five interviews. Both the Motor Neurone Disease Association (MNDA) and the Huntington's Disease Association worked closely with the neurology clinics based in Birmingham, and may have been providing services to some of the participants. BME service users could therefore be targeted through mainstream charities in the future as they may be receiving services from both the NHS and charities. The disease-specific charities were all interested in the research and were willing to put details of the research on their websites and newsletters. However, one charity (MNDA) was aware that some people could feel over-researched. In order to support research and to protect people from feeling over-researched, they created a register of people who were willing to be contacted about new research, and these people could then directly approach

researchers if they were interested. This was effective as there were far more enquiries about the research from this charity than all the other charities.

The other strategies used were not as successful in terms of participant recruitment for interviews. Although steps were taken to promote understanding in the different communities as suggested by the literature (Mohammadi et al., 2008; Sheikh et al., 2009), the rarity of the conditions meant that very few people had heard of the conditions, and no-one was aware of anyone with these conditions. None of the participants identified through the neurology clinics mentioned that they had seen the study advertised at a local temple or heard about it on the radio. A number of participants mentioned in interview that they had become withdrawn from community events since diagnosis, as had their carers. This could partly explain the lack of recruitment and eligible participants identified from the community targeted strategies.

Stigma associated with some of the conditions, especially those with a genetic element may also have contributed to difficulties in identifying suitable participants. Historically Huntington's disease was stigmatised with compulsory sterilisation advocated in the US and in Germany (Wexler, 2010). Although the focus has now changed, the stigma remains. Stigma may be problematic in cultures where arranged marriages are common, or where religious beliefs lead to service users and carers thinking that the condition is some kind of punishment. A study exploring religious beliefs about epilepsy found that Muslims believed the cause to be 'God's will' and Hindus and Sikhs believed it to be fate (Ismail et al. 2005). Another study found that

people sometimes concealed a diagnosis of dementia so that marriage arrangements would not be compromised (Mackenzie, 2006). The contact details for the study were of someone who was of Indian origin, and this may have acted as a barrier to initial contact if stigma was a factor.

Ethnic matching is a strategy that is promoted in health services research (McLean and Campbell 2003). Coleman-Bruekheimer, Spitzer and Koffman (2009) were interested in medical decision making by Haredi Jews with breast cancer. They noted that Haredi Jews are a tight-knit community and that they hoped to maximise communication and trust with their participants by ethnic matching. One researcher was a Haredi Jew but in a different community from the participants, and the other researchers were Jewish (not Haredi). They felt that this was helpful as the researchers would understand the various issues that would arise, and as they were from separate communities, the participants would be able to discuss sensitive issues with full confidence that confidentiality would be maintained.

Despite the researcher not falling into the main religious and ethnic communities in Birmingham, researcher ethnicity did work against recruitment in one case. One person did contact the researcher and enquired about the study. Initially they were interested in the study, but were concerned about the origin of the researcher. They stated that no-one in their community was aware of the condition, and that they didn't want it to become known. They did disclose that they were minimising the services they were receiving to try and keep the diagnosis secret. Although they received assurances that confidentiality would be maintained at all times, and that the

researcher was not in the same community, they declined to participate in an interview.

Snowball sampling was unsuccessful primarily because the participants that were interviewed did not know other service users. Snowball sampling was an effective recruitment strategy used by Douglas et al (2011), but their area of research was diabetes, which is relatively common and has a higher proportion of people from some ethnic groups. The only service users that may have known other people with the condition were people with a genetic condition such as Huntington's. However, stigma associated with Huntington's may have been the reason they did not suggest anyone. For snowball sampling to be effective, the sample being researched have to have some common link (Faugier & Sargeant, 1997).

The main reason for the lack of recruitment from these community-targeted strategies, in conjunction with those mentioned above, is the rare nature of the conditions studied. The neurology clinics and the condition-specific charities may have been the only successful recruiters because they had the target audience of people with the rare conditions. The high recruitment levels through the neurology clinics may have been due to the personal nature of the invitation to participate. Participants may have appreciated a research nurse explaining the study and therefore were more willing to participate. Rooney et al (2011) suggested that a more personal approach to recruitment might be more effective.

Although all the methods were not directly successful in recruiting participants into the study, the study itself did generate a great deal of interest. It is possible that the lack of recruitment did not stem from the BME communities being unwilling, rather due to the rare nature of the diseases, they were ineligible for interview. Based on the responses received from the community, if individuals been eligible then they would have been willing and interested to take part. Despite not leading directly to recruitment, there were some benefits in carrying out these methods. For example, researcher views and stereotypes were found to be problematic in another study (Sheikh et al., 2009). In addition, learning to behave appropriately and non-offensively improved recruitment in another study (Thompson, Neighbors, Munday, & Jackson 1996).

Attending temples, meeting community leaders and meeting different communities helped to understand cultures and may have ultimately helped when consenting and interviewing participants recruited from the more successful non-community methods.

4.4 Conclusions

Future studies should plan ahead and steps should be taken to understand where potential participants are likely to be. BME participants are not ‘hard to reach’ but researchers do need to look in the right places to enhance recruitment. Researchers need to consider the prevalence of conditions, and perhaps the more common conditions, such as diabetes and hypertension, would benefit from alternative methods of recruitment. These methods would be particularly effective for recruiting people who were not known to services. The majority of people were responsive to

research and showed an interest. The reason community based methods were not effective was because community members had generally not heard of any of the conditions. For rare neurological conditions, people would have had to be known to services for them to have such a diagnosis, and the low prevalence of the conditions meant that it was unlikely that potential participants would be found at various community events or centres. A more time and resource-efficient method in such rare conditions would have been to concentrate recruitment on specialist neurology clinics in large metropolitan areas with ethnic diversity and with developing relationships with the disease-specific charities who in some instances have websites and newsletters that have a separate research section. The health professionals were interested in the study, but importantly, they had time to mention the study and explain what it involved. In addition, participants may have liked the personal approach to participation, rather than receiving a letter or seeing an advertisement.

However, even in such rare diseases, community based strategies used here may be worthwhile on a smaller scale as getting to know and understand the local community was valuable, and potentially helped to improve consent rates and the quality of interviews.

5. RESULTS

5.1 Demographic data

Fifteen interviews with service users and carers were undertaken in total. Five of the service users interviewed contacted researchers directly after seeing the study in a charity newsletter, and the other 10 were recruited through NHS clinics. Another six people were directed to the study through the clinics, but declined to participate. One further individual responded to the study after seeing it advertised in a charity newsletter but was ineligible to participate as he was pending diagnosis at the time. Thus, the overall recruitment rate for the study was 71.4% (15 out of 21). The interviews were undertaken with service users and in three cases, carers only. In one interview, the service experiences of two service users were given as they were brother and sister, both of whom had HD. Table 5.1 outlines the sociodemographic details of each of the service users who participated. It also includes whether a carer was present and the relationship to the service user. There is some missing data because some individuals declined to provide their age and/or religion.

Table 5.1 Sociodemographic details of participating service users

Service user ID	Ethnicity	Gender	Age	Main language at home	Religion	Carer present at interview?
MND101	Pakistani	Male	56	English		Yes (Wife)
MND102	White Other	Male	79	Spanish		Yes (Wife)
MND103	Pakistani	Female		Urdu	Islam	Yes (Son)

MND104	Indian	Female	67	Hindi	Hindu	Yes (Husband)
MND105	Pakistani	Female		Urdu	Islam	Yes (Daughter)
HD101	Mixed race	Female	37	English	Christian	Yes (Partner)
HD102	Indian	Male	49	English	Sikh	No
HD103a	Indian	Male	22	Gujarati		Yes (Mother and her partner)
HD103b	Indian	Female	27	Gujarati		Yes (Mother and her partner)
HD104	Indian	Male				Yes
PPS101	White Other	Female	69	English		No
PPS102	Pakistani	Male	49	English	Islam	No
PPS103	Pakistani	Female	50	English	Islam	No
MSA101	White Other	Male		English		Yes (Wife)
MSA102	Indian	Female		Gujarati	Hindu	Yes (Husband and Son)
CMT101	Indian	Male	65	Punjabi and English	Hindu	No

5.2 Summary of themes

Following thematic analysis of the interview transcripts (see chapter 3 for a detailed account of the analytical methods used), five overarching themes were identified, some of which also encompassed a number of sub-themes. These themes and sub-themes, and their supporting data, via verbatim quotations from the interview transcripts, are outlined in the remainder of this chapter.

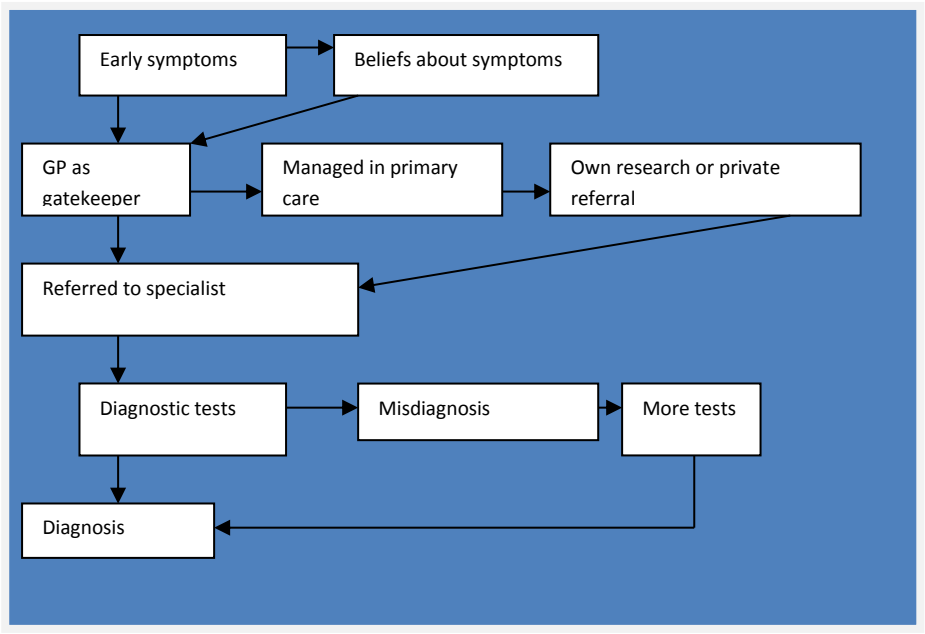
Presentation of each theme is organised around the stage of the 'patient journey' being referred to by research participants, so that the patient's pathway through the health and social care system from initial help-seeking, through referral and diagnosis and subsequent treatment is described, and barriers and facilitators to care are identified at each of these stages. The overarching themes and sub-themes identified from the interviews were as follows:

1. *Pathways to care*: Including early symptoms, when and why patients visited their GP, the speed and appropriateness of referral, diagnostic tests undertaken, and diagnosis
2. *Care received*: Including details of NHS care, social services support, voluntary sector support, and co-ordinated care
3. *Family support*
4. *Isolation and stigma*

5.3 Pathways to care

Service users and carers described how and why they entered the healthcare system, and the barriers that they faced. The service users presented to their GP with initial symptoms, and the GP in their role either managed the service user in primary care, or they referred them on to a specialist. Figure 5.1 below shows a service user's journey from initial symptoms to diagnosis as found from the interviews.

Figure 5.1: The service user 'journey' from initial symptoms to diagnosis



5.3.1 Early symptoms

Many of the service users described what their earliest symptoms had been, and none of the research participants reported visiting their GP immediately upon

experiencing symptoms. However, the main barriers to care identified in the literature review (language, awareness of services) were not the reasons that service users gave for this. The reasons for non-attendance varied, and service users had different understandings or beliefs about what was happening to them. Service users described a variety of early symptoms all of which became apparent very gradually. Interestingly, it was often loved ones that noticed something was wrong because the onset of symptoms was so gradual. For example, two service users experienced problems with their speech. In one case they initially thought it might be due to a cold:

"…she's a very good singer and she would sing the hymns in the temple and people used to be looking at her, what happened to her, they thought she might have had a cold or something" Carer MND104

Another carer noticed that her mother had a pain in her arm, and as it was so gradual, noticed that she was helping her more of the time:

"I just started noticing my, she used to ask me to help her" Carer MND105

As the symptoms were typically subtle and gradual, many of the service users could look back and say with hindsight what the initial symptoms may have been, but at the time they were first experienced, these were often ascribed to age-related aches and pains. The rarity of the conditions and the difficulties in diagnosing them suggest that recognition of early symptoms would be unlikely in any population.

Unlike the other service users, the HD service users had a parent that had died from HD, so were aware that they were genetically pre-disposed to the condition and knew of the risk. However, in two cases, it was the service user's partner who had noticed that something was wrong and suggested that the service user ought to be tested. Those who live closely with individuals showing early symptoms were more likely to notice changes (e.g. to personality or cognitive function) that the service user was not aware of. Studies have shown that insight and awareness of the condition is evident in people that are pre-diagnosed with HD.

5.3.2 GP as gatekeeper

The majority of service users in this study were persuaded by loved ones to visit the GP because they had noticed changes. Many service users and their families reported having long standing relationships with their GP and therefore attending the GP was not a barrier to care for participants in this study. However, the GP at this point had to make one of two choices; they recognised the need for a specialist and referred the service user on to secondary care, or they managed the service user in primary care.

5.3.2.1 Referred to a specialist

All of the HD service users were immediately referred to a specialist as their history of HD was known to services. Therefore the fact that GPs are gatekeepers to secondary care was not a barrier to receiving specialist support in these instances, and awareness of family history helped with this.

A service user with MND went to the GP on the insistence of his wife because his speech had deteriorated and his gait had altered:

"We were in Turkey and his walk and his speech, we didn't take any notice of it, but when we came back his speech was getting worse" Carer, MND101

He was referred immediately to a cardiac unit for tests as he had a history of cardiac problems and the GP initially suspected he might have suffered a stroke. Another MND service user, also with a speech problem, was referred privately as her daughter and son-in-law both worked in a health-related field. This service user said that both her daughter and son-in-law had believed that she had MND but they did not disclose this to her at this time.

5.3.2.2 Managed in primary care

The other service users' care needs were initially managed in primary care. When there was no improvement in symptoms, people were referred to specialists; some with no difficulties at all. In contrast, some service users felt badly treated by their GP. One service user with PPS was frustrated by her GP because he attributed all her symptoms to an existing disability (caused by polio) and suggested that PPS did not exist. She was eventually referred to a neurologist specialising in PPS when she was seen by a different GP:

“he is very dismissive and he was like you know with any ailments basically “oh it’s because of your disability” but when I’m saying to him but this is happening to me “oh it’s because you know, there’s no such thing, you know it’s just a myth” Service user, PPS103

So, although many people value continuity of care, it was fortunate that this service user was seen by a GP who did not know her personal history so that she could be referred to a specialist.

Some service users were very persistent with their GP. One service user said that he contacted his GP every week after his GP mentioned the possibility of referral to a neurologist. He said that he contacted him repeatedly because he wanted to know what was wrong. Another service user who had been to the GP about problems with her back said that she kept going back to her GP and asked to be referred to a specialist. The GP eventually made the requested referral but said that there would be a long wait. Another service user felt so unhappy with his primary care service that he changed GP. It was unclear how frequently he went to his GP but it seemed that the GP was unwilling to refer him to a specialist in the local area:

“He said there is nothing I can do, I said look I don’t want to keep commuting to London, there has got to be something locally here, there’s nothing what do you want me to do? I said you’re my GP and the way his attitude was, so that as soon as I came in he said he would press the buzzer for the next patient” Service user, PPS102

Nazroo et al (2009) analysed data from the Health Survey for England (HSE) and found that people from BME groups were no less likely than other ethnic groups to use GP services, but that there were inequalities in the use of secondary care. The experiences of the service users in this study sample suggest that GPs may be less likely to refer BME patients.

Contrary to much of the literature on barriers to care for BME groups, language did not appear to be a major barrier for the majority of service users in this study. Some service users were able to speak English well so did not have trouble communicating with their GP. Some service users who did not speak English had a carer who spoke English well, and the carer was able to communicate the problems to the GP.

However, although using a carer to translate is often the only available solution at the time, it is not always problem-free. One service user who did not speak English attended the GP appointment with her daughter, but did not understand what had happened in the consultation, as she was sent home with antidepressants for leg pain. This example highlights the potential importance of the use of interpreters in health and social care appointments. It enables service users to take responsibility for their own care, and removes the possibility of carers not disclosing the full consultation to the service user.

Manthorpe et al (2009) undertook a survey that found that one BME group was only likely to visit their GP once their symptoms had become severe because they were

not able to communicate in English, and because translation services were inadequate (Manthorpe, Iliffe, Moriarty, Cornes, Clough, Bright, & Rapaport 2009). However, the need to address language issues within healthcare services has been recognised by many GPs, especially in ethnically diverse areas. Greenhalgh et al (2007) found that many GP practices in such areas recruit bilingual GPs in order to improve the care received by their BME service users (Greenhalgh, Voisey, & Robb 2007).

Therefore, although all participants had been symptomatic for some time, only the HD participants were referred for specialist care and testing immediately. Many of the symptoms with which service users presented to their GP could have been indicative of a range of less serious conditions, and with shortages in the availability of neurologists in the UK, waiting for symptoms to subside before referring on to specialist services may have been the best or only course of action available to GPs. The main barriers to care which are often cited in the literature, such as knowledge of services and language barriers, were not apparent in accessing GP care for the majority of service users interviewed for this study.

5.3.3 Referral to a specialist and diagnosis

Prompt diagnosis for these conditions is vital so that any available treatment can be started as soon as possible, and so that ongoing care packages can be put into place.

Diagnosis of some neurological conditions can be extremely difficult for conditions that lack a genetic component, and this difficulty in reaching a definitive diagnosis was evident in this set of service users. For example, with MND, many other conditions enter the differential diagnosis, which have to be ruled out before a diagnosis of MND can be made. All service users were required to undergo many different neurological tests, and length of time to diagnosis varied extensively. Cellura et al (2012) found that 31.1% of the MND service users in their sample had been misdiagnosed, and that this led to delays in diagnosis. They found that it took a median of 15 months for members of their study population if they had been misdiagnosed versus nine months if they had not (Cellura et al. 2012). The MND service users in this study had accepted that other conditions needed to be ruled out before they could be given a diagnosis. One MND service user who had a private referral took only four months to receive a definitive diagnosis, although this was unusual, and may have been because her daughter and son-in-law were aware that her symptoms may have been related to MND. Other MND service users who were referred through the NHS took a minimum of eight months to diagnose. However, language difficulties did not seem to prolong the time taken to diagnose the MND service users, and nor did their level of knowledge and awareness of services.

One MSA service user waited several years to receive an accurate diagnosis. MSA is often initially misdiagnosed as Parkinson's disease (PD) due to the similarity of symptoms across the two conditions. The Scottish Intercollegiate Guidelines Network (SIGN) guidelines highlight the difficulty of diagnosing Parkinsonism conditions and state that only a post mortem can confirm a true diagnosis but do also state that

accurate diagnosis is essential for treatment (SIGN 113 Diagnosis and pharmacological management of Parkinson's disease, 2010).

However, this service user was dissatisfied with the consultant she was seen by in this country and went overseas for a second opinion. The overseas consultant diagnosed PD and began a course of PD medication immediately. On their return to the UK, they went to see the consultant who said that he believed this to be the case all along:

"…look we've been to India, we've had an opinion out there and they have said its Parkinson's disease, that's when he said, that's what I'm thinking. Which at that stage, you think well I've got no confidence in you at all, because we went all the way there for you to tell me that's what you were thinking now" Carer, MSA 102

When asked whether they had challenged the consultant or mentioned that they were unhappy, the carer said that he didn't want to cause trouble for his mother:

"No, I didn't, because he was treating mum, I didn't want to cause any aggro you know because he's treating my mum so I thought I'm going to have to let it go. But that's when my faith in him/the system faded a little bit" Carer, MSA102

He also went on to suggest that the consultant would not have listened to what he had to say. Peters et al (2012) reported that caregivers in their study felt that they were not listened to, nor were they involved enough in the planning of care for people

with MND (Peters et al. 2012). This may mean that carers in general do not feel listened to, rather than BME service users specifically.

However, the carer in this study did also say that the consultant probably had many years' experience and that perhaps he had wanted to wait until all the tests had been completed:

"Like all specialists, they've probably got a little bit of a 'what I say goes' mentality, so you think it's probably not worth it. I'm sure the guy knows what he's doing, he's an experienced guy, 20 years in the field but for him to say that after we came back. Maybe he's genuinely said, until I do all the tests I don't think I should tell people and worry them unnecessarily, possibly, you don't know." Carer, MSA102

Despite this, the family did not trust the consultant but felt unable to say that they were unhappy with care. Mead and Roland (2009) did a cross sectional analysis of a routine GP patient survey and found that ethnic minority groups rated their care more negatively than White British, and that cultural and language impacted on the level of negativity. So although service users express that they are unhappy with the type of care they receive, whether they then go on to make a complaint is not known.

Another carer (MND102) also spoke about unhappiness with the care received but did not want to complain because she too was concerned about the impact that complaining may have had on the quality of ongoing care offered to them. Therefore, feeling reliant on services did make some people reluctant to complain, although

there could have been other reasons for this. Lawton et al (2006) found that Indians and Pakistanis may have been reluctant to complain about their diabetes care because it was free (Lawton et al. 2006).

Not all service users were reluctant to change health professionals if they were not content with the service being provided. One service user underwent a test in defiance of the consultant's belief that it would not provide any further information. The consultant had also disagreed with the service user about the existence of PPS. When she asked for a second opinion, the consultant asked one of his team members to see the service user. This doctor said that she would not disagree with what the consultant said because they were in the same team.

"The first second opinion I had was a lady doctor [Name of doctor] who was subordinate to that neurologist [Name of doctor] who didn't agree that there was such a thing as Post Polio Syndrome, and she said I can't do anything because he's my superior, I can't go against him." Service user, PPS101

Despite these setbacks in her care, the service user persisted and asked to be referred elsewhere until she was satisfied with the care and with her diagnosis.

There are a number of differences between these service users, and they may explain why two of the service users didn't complain and why one service user did complain. Both MND and MSA are difficult to diagnose, but it is accepted that they exist and can be diagnosed eventually. With PPS, there seems to be a debate

amongst neurologists about its existence. As the service user who had PPS was well aware of the information about PPS, and the difficulties in diagnosis, this may have made her more confident about expressing her wishes.

Medical tourism is not a new phenomenon, and as the NHS has limited capacity, it is not unusual for people to seek help from abroad. The MSA service user was not unique in going abroad for a second opinion. One HD carer was certain that her son was presenting with symptoms of HD from a young age. He was having difficulties at school and he had been under the care of a neurologist for two years. The neurologist had said that to confirm a diagnosis of HD, he would need to have a genetic test. The carer said that she then decided to take her son to India. The Indian neurologist confirmed that her son had symptoms of HD and that he would need to have a genetic test for a definitive diagnosis. She brought her son back home and got a genetic test done. When questioned about the decision to go to India, the service user said that she was able to better understand the nature of HD over there:

"they just gave us more specific answers rather than here, they said Huntington's disease is probably in every generation, more advanced, I learnt it from India." Carer, HD103

Therefore, with both HD103 and MSA102, the reason for going abroad was not because of waiting lists or the difficulty of obtaining referral or specialist appointments, but because travelling abroad meant that they were able to express more clearly what they wanted. So although language was not overtly a barrier to

receiving a referral or obtaining a definitive diagnosis, it may have been an important factor indirectly. Having to explain complicated symptoms in a second language is, for many, more difficult than doing so in their first language. In addition, some BME service users and carers may have more faith in the healthcare system of their home country.

Although the MSA service user was dissatisfied with their consultant, it did not prevent them asking for tests that they had been advised to obtain from an overseas doctor:

"He said "well I don't know if it will tell me anymore because with this condition there are no tests, there's no medication, but it's a very expensive test. With that amount of money, I can probably treat 10 patients"…Well I'm sure you've got an obligation here where you have got a patient in front of you to know what's going on" Carer MSA102

The consultant was obliged to work under the constraints of the NHS, and justifying the cost of a test is an essential part of their work, and sometimes out of their control. However, the guidelines in the National Service Framework for Long Term Neurological Conditions (NSF LTNC) clearly state that accurate diagnosis is essential so declining to offer a test on the basis that there is no treatment available for the suspected condition does not seem to be acceptable.

5.4 Care

Once service users had been diagnosed, they recounted varying experiences of care offered by the NHS, social services and the voluntary sector. In addition, there were different experiences of coordinated care and inter-agency working between these three sectors. Language barriers, knowledge and information about services, and culture and stigma were apparent for social care services, and not for the NHS, and shall be described below.

5.4.1 The NHS

Once service users had been diagnosed, the level of services available to them varied greatly.

The CMT service user was offered annual appointments with his neurologist in order to monitor any changes to his CMT. He had also been given splints, but there was nothing more that could be offered by the NHS for CMT.

This also appeared to be the case for the majority of MND service users. They had appointments with their neurologist for monitoring changes, but little else could be offered by means of ongoing care. They had all been offered Riluzole, a drug for MND which can extend a sufferer's life by up to six months. However, only one service user had opted for this drug. One of the service users had been provided with a speech and language therapist, but as his symptoms worsened, there was little that could be offered.

The PPS service users had been offered varying levels of care. Service user PPS101 had been offered orthotics, but stated that it had taken over 18 months to organise, so had given up pursuing it any further. PPS103 was recovering from surgery, so had not yet sought PPS-specific support, and PPS102 had stopped attending annual neurology appointments because he was reluctant to travel to London, and was unaware of appropriate services locally. PPS102 was the service user who had described a difficult relationship with his GP and had therefore not been referred to local services.

As HD symptoms could be managed to some degree, HD service users received the greatest input from the NHS. These service users were under the care of HD services, and would have appointments every three to six months. They also had a key worker allocated to them who would make regular visits to them in their homes. These service users also had contact details for their keyworkers and could contact them when they needed to.

Information needs seemed to be met for the MND and HD service users. The MND service users were provided with a folder of information at the point of diagnosis. This contained information about MND, the services that were available, and support groups. Most of the service users and carers found this to be helpful, although not everyone felt this way. MND105 said that she didn't want to look in the folder and read about MND as she didn't want to know what was going to happen:

“It maybe something, I can’t look at it” and *“Something I’ll read and I’ll never forget”* MND105

Although the service user was reluctant to look at the information, the carer said that they knew to look in the folder if they needed to know what services to contact if such services were needed.

It seemed as if MND services had responded to the needs of service users and carers by providing information that they could use throughout their illness. In addition, MND service users stated that they had someone that they could contact if they needed help with accessing any services.

Therefore, although the level of NHS care varied between all service users and between the conditions, language and information barriers were not apparent with these service users. Stigma was also not evident with the uptake of NHS services. Whether services had responded to the specific needs of BME service users by providing them with information and a contact person was not known, but in this study sample, it was a valued element of care.

5.4.2 Social care

The experiences of social care varied greatly in this study sample. All of the service users were in varying need of social care, and there were a number of social care providers available.

The barriers that have been highlighted in other studies, such as access to services, stigma, and expectations of care, were all apparent and shall be described below. It was carers that dealt predominantly with social services, as service users were often too unwell to deal with social services directly when it came to needing their support.

5.4.2.1 Access to services

Social services were difficult to access for one carer in particular (MSA102 Carer) because there was a telephone access system rather than an allocated social worker:

"Yes if we need something, social worker wise, we just phone social services and they put you on to the next available social worker. The social worker we had originally, if you don't need anything you're dismissed, but if you need anything you just give them a call, which I think is a bit daft, because they know you're history it would make sense for them to come out but I suppose work log wise.." Carer, MSA102

As the quotation highlights, the lack of an allocated social worker who knew the medical history of the service user meant that there was no ongoing knowledge of the service user's needs, and the carer would have to explain the situation each time that social services were contacted. As the service user could not speak English, and because the main carer had limited English, it fell to this carer to organise social care. This carer had his own family and worked full time, so negotiating social

services was extremely difficult for him. It was unclear what social services would have done if this carer did not have capacity to phone on behalf of the service user. Having a telephone only system makes it difficult to access care not only for individuals with limited English competence, but also for those with speech problems, which was commonly encountered in this study sample.

This same carer also stated that there was no coherent information that was provided by social services, and that it was difficult to know what was available, and where to look:

"So there was a young lady that came out, a social worker, she might have been new I don't know, she might not know but I asked about it and she said I don't know I must look into it, I'll try and find out, so I've spoken to somebody else at work whose mum is disabled, and he said there is this. I found out the number by phoning the council and I said look there's got to be something somewhere and I got a number, so there is something available. Since then my brother's found out a chap that does adaptation for work and he's on the panel at the council, and I spoke to him and he said yes the councils put to one side a lot of money for this type of thing. Well if they've done that they should tell people." Carer, MSA102

This carer went on to say that it would have been helpful if social services had a list of available services outlined clearly on a website. How someone with language difficulties would have accessed these services is not clear, and information and awareness of services was clearly lacking.

However, another carer (MND102) described a very different experience with social services. This social services was in a different area, so the provider was different, as was the system. This carer could not speak very much English and she said that social services had been extremely helpful, and that there was a single point of contact made available for her to communicate with if she needed anything. It was not clear if this care provider operated this service for all patients or whether it was only available to BME service users.

In this study sample, the people that contacted social services had a good level of English, apart from the one carer discussed above, and that made her experience unique.

5.4.2.2 Stigma

Another emergent theme that was apparent when people described their experiences with social care was stigma which was influenced by cultural issues.

The service users had different needs where social services were concerned. Those that had been recently diagnosed had not been in contact with social services as they had no need for them. This was the case for MND104, who although she had some mobility issues, wanted to wait as long as possible before contacting social services. This was also the case for PPS101, who said felt that if she had adaptations installed, she would lose the ability to perform the tasks that the adaptations were designed to facilitate.

However, CMT101 spoke at great length about feeling embarrassed by having any disability, and having formal changes made to his home would have been one step too far. He was even reluctant to use his disabled parking badge in front of other people because he was concerned about what they would think. The difference between accepting NHS services and social services here is the relative visibility of something being wrong. NHS consultations are completely confidential, such that their use is anonymous and others would not know if an individual was accessing NHS services. In contrast, the use of social services may entail visible changes to one's home and living environment that would be obvious to others and a potential source of stigma.

Therefore, stigma may have been a factor in accessing social care, but cultural factors related to expectations of care also played a part.

5.4.2.3 Expectations of care

PPS102 stated that he had bought a house knowing that he would need to have wheelchair access and modifications made to the property. However, he was surprised when social services said that they were not prepared to pay for changes to his home in advance of him needing them. This service user was attempting to prepare for his eventual disability, and thought that social services would agree to this.

This service user perceived this decision as racism and may not have understood that social services work within rigid guidelines, and advanced planning may not have been an option. Lack of understanding of social services and because the service is means tested led to higher expectations of the level and extent of care that would be available for many service users.

One carer (MND103) said that he had wanted to install a new bathroom downstairs so that his mother could wash. She was regularly being hosed down in the garden because there were no appropriate wash facilities accessible to her on the ground floor of the property. This was an unacceptable situation, but after further probing, it emerged that the fault lay between both social services and the family. Social services had delayed the assessment process, and only after intervention by an MP did they 'upgrade' the assessment to urgent. However, the means testing assessment revealed that the service user would have to pay the full cost of any adaptation. The family then believed that they should be entitled to have an extension built instead, and because they wanted to do this, they were waiting for planning permission.

There was anger from this carer because they experienced a long delay in their assessment at a time when their perceived need was so urgent. However, what appeared to make the situation worse was being told that they would have to pay the full cost of any changes to the home. They said that if they had been informed of this earlier, they would not have waited for an assessment.

The above two cases show that people expect much greater levels of care than it may be possible for (often over-stretched) services to provide. The carer for MND103 felt that his mother would have received a higher level of care in Pakistan. The view that people would have received a better level of care abroad (in their 'home' country) was echoed by some service users and carers:

"I wouldn't rely on this council for anything honestly, they just, you get better service in Pakistan, honestly, that's honestly what I think" Carer, MND103

The negative evaluation of social care is in stark contrast to the NHS care that people received. Service users and carers understood that the conditions were not curable, and often the NHS could offer little in terms of services. That may not have been the only reason that service users and carers were more forgiving of the NHS, however. Service users and carers may have been grateful for NHS care as they perceived it to be free. Social services care is means tested, and many of the service users were required to contribute to their care. Being required to contribute to care may have led service users to believe that they could have a greater degree of choice, and may therefore have created greater expectations of care.

The reality is that social services have limited capacity to provide care, and that these services must operate within very rigid guidelines and financial restrictions.

The expectation of service users and carers seemed to vary with how much they were required to contribute to their care in financial terms.

Neither MND105 or HD101 needed to contribute to their care from social services, and their expectations differed from those of the service users that did need to pay for services received. HD101 was living in unsuitable housing and was on a waiting list to move to a more appropriate house. Although she had been waiting for a long time, she understood the constraints, and did not mind waiting. MND105 was waiting to have a ramp installed so that she could leave her house in her wheelchair. There had been a delay, but that was a result of her children not working together to arrange the care. The carer that was present said that their social services offered them too much choice. The onus was on service users and carers to obtain quotes for building or adaptation work and social services would then agree to facilitate the changes. This meant that service users would have more choice in who did the work for them, but this particular carer found it burdensome, and experienced delays.

5.4.3 Voluntary sector

The voluntary sector provided a great deal of support to members of this study sample. For the MND and HD service users, the Motor Neurone Disease Association (MNDA) and the Huntington's Disease Association (HDA) were actively involved in providing care, and seemed to be embedded into NHS teams. Quite often, service users and carers did not know if some of the professionals they were dealing with had come from the voluntary sector or not, but their help was seen as invaluable.

The carer for HD103 stated that the worker from the HDA had been indispensable, and that her input meant that she was able to get extra support from the school for her son:

"She come along every time and explained to the school or the social worker and everything, and then we get the staff helping [Name of son] to the class, someone can hold his bag and transfer him to the one to one room" Carer, HD103

Some of the MND service users mentioned that they were able to access vital equipment (such as communication equipment and wheelchairs) from the MNDA, and this made things a little easier. The folder of information that people received upon diagnosis contained information about services that were provided by MNDA, and contact details.

Both the MNDA and HDA are large, well-funded organisations which were able to offer a high level of support. The British Polio Fellowship (BPF) provided regular newsletters, arranged conferences, and provided benefits advice. There was a mixed response from the PPS service users about the usefulness of the BPF. PPS101 said that BPF had helped her to obtain disability living allowance. PPS102 said that he had contacted BPF as he wanted to set up a local support group as his nearest existing groups was some distance away. He wanted the BPF to advertise the group, but they were unable to do this:

"I said I'm quite happy to, I've spoken to the central office and I've said I'm happy to run a group here for people in this area can you put that forward, if I put it forward nobody would do it, if they do it thankfully there will be somebody interested but nothing happened." Service user PPS102

This service user believed that if the BPF had endorsed the group, it would have carried more weight, but limited resources would have prevented the BPF from endorsing every proposed support group, so there was disjuncture between the kind of support the service user wanted and what was possible within the organisational resources available.

PPS103 was also disappointed with the BPF, again expressing greater expectations of the organisation than was realistically possible. She asked for their advice when her benefits application was turned down. The application for benefits was refused because she had two houses, including one that had belonged to her (deceased) parents. This service user had sentimental reasons for keeping the house, but because of the house's value, she was not entitled to receive benefits, and the BPF could not have changed that. They had suggested that the service user should sell her house to be able to get the support she required, but she refused to take their advice.

One carer (MSA102) said that he had heard of the Sarah Matheson Trust (now called MSA Trust) but he felt that although they were able to provide some information about MSA, there was little else they could do:

"More understanding, a little bit, but for everything else not really because what else can they do?" Carer, MSA102

He said that they were a small charity and that they would not have availability or capacity to help other than to give advice.

What was noticeable about the use of the voluntary sector was that no barriers to care were apparent in this study sample. Neither cultural, or language barriers affected their use despite the fact that such voluntary services did not make specific concessions to members of BME groups. Knowledge of services was also not a barrier, possibly because most voluntary organisations were strongly affiliated with NHS services. The issue of co-ordinated care is discussed in the next section.

5.4.4 Co-ordinated care

There was some evidence that co-ordination of care occurred. For example, HD101 had regular review meetings that involved a key worker who would report any changes to HD101's care. It was not clear who was involved, but it seemed to be the NHS, social services and the HDA.

"Its like treatment and care for people whose got Huntington's, Parkinson's, Alzheimer's, it's a team based in [Name of area] and they come out every 3 months and have a meeting to see what she might need" Carer, HD101

In addition, through the HDA, this service user was able to access equipment provided by the NHS because they all worked closely together. The carer went on to describe how a wheelchair was organised:

"Yes, they organised it through the NHS, they organised a lot of things. She's got a cape that is resistant to fire and things." Carer, HD101

Like much of the care received, it was dependent on the area in which an individual lived, and the service users were from a wide geographical area which meant that coordinated care was not available to everyone to the extent experienced by the carer above.

Most MND service users had a key worker that they could contact who would be able to advise and help with form filling if required. MND NHS services seemed to work very closely with the MNDA so were able to provide specialist workers who were well trained and who understood the kinds of changes that would occur with service users and the support they might require as a consequence. Although this coordinated working did not extend to social care, the MND service users and carers valued the specialist workers and were not interested in what organisation they belonged to, only that they could offer the support that they required.

This co-ordinated working was not apparent for the remainder of the service users, although this was probably because PPS, MSA, and CMT are even rarer and less

well heard of, and the resources are unavailable to facilitate specialist workers to aid carers and service users.

5.5 Family support

The majority of service users (14 out of 15) had some form of support from their family members, and in many instances, members of the family were present during the interview. However, the extent to which family members were directly involved in service users' care varied considerably.

Despite a stereotype that Asian families look after their own, this was not the case for many of these service users. For example, MND104 had been recently diagnosed with MND, and despite having four children, this service user and carer was aware of the limitations of the support they could offer because they had their own lives:

"She's working in a company, she comes to when she can, every month or something like that. They support us if we've got any problems or anything like that but they can't look after her, they can't come here any time that we want." Carer, MND104

Conversely, the carer for MSA102, who was the service user's son, spoke of the difficulty of managing his mother's care, and juggling that with his own responsibilities. He worked full time and was married with two children. He said that it was becoming increasingly difficult to manage it all.

Despite the differences in family circumstances, it was more difficult for MSA102 and her husband to manage despite the help of their son because their level of English was not as good as MND104 and her husband, so trying to negotiate any care would have been much more difficult for them if their son had not been involved in the caring responsibilities.

One service user (MND105) had been living with her husband, her son and his wife. This service user and her husband were both disabled and were entitled to carers provided by social services. However, she was not content with the level of care she was receiving, saying that the carers were not there long enough for her to have a proper wash. Her son was planning to move out, and this was with the hope that social services would provide more care as a result. Therefore, some BME service users may have had the belief that social services would offer more support if there was no extended family.

PPS103 had no family at all to support her. She was estranged from her family, and said that she had always been independent when she was disabled by her original polio. However, she had become even more disabled and stated that she had no-one:

"I've always been independent and you know, the onus is on you, when you're going through, that's what I was trying to say to anybody when you're actually, there's an assumption that you've always got friends and family, you've always got children or

family or carers or whatever. Some of us aren't that privileged. Some of us are on our own" Service user, PPS103

This service user was finding increasing disability very difficult and found the lack of friends and family very noticeable. She was in a situation where she could not afford to pay for carers to come into her home because she was no longer working. She did have a friend that was helping her out, but she did not know how long this would continue.

5.6 Isolation and stigma

All of the conditions investigated in this study are progressive and neurodegenerative, so mobility will be affected and increasing disability will be evident. Therefore, when asked about leisure activities, most service users and carers stated that they had been greatly reduced because of their changing needs.

For example, the carer for MND101 stated that they were no longer able to go out because of her husband's disability, and because there wasn't any time. She was struggling to keep paying the mortgage so had to work full time, but also had to care for her husband full time. They both said they also found it frustrating being around people that were unable to understand her husband. His speech was greatly affected, and he said that he lacked patience for people that tried to 'guess' what he had to say, rather than trying to let him speak for himself:

"Interviewer What they try to finish what you're saying or something?

Service user Yes or they try and talk over you" Service user, MND101

This service user also had trouble getting an appropriate wheelchair, so combined with his speech difficulties, he spent long periods of the day on his own whilst his wife was out at work. Specialist speech software from the MNDA had helped, although that was also problematic because his laptop was not fit for purpose.

So, the service user above experienced isolation because of his disability, and lacking the correct equipment or support to enable him to do more social activities. Other service users spoke about increased isolation in a different context. Some of the South Asian service users had been regular attenders of their local temple or community centre, but had reduced or stopped this after their diagnosis. They were still physically able to attend, and they would have been able to contribute, but chose not to go. MSA102 said that she didn't want to go to the temple anymore, and did not enjoy going to the day centre once a week, despite the fact that her husband and son had arranged for her to attend the day centre and were keen for her to attend in order to provide some respite for her husband, but she simply did not want to go.

MND104 had been very active in the temple before her diagnosis, and also stated that she didn't want to go any more. Her husband said that she didn't even like it when people came to their home:

"Oh yes, she don't want to see them, I don't know why. When they ring she always makes the excuses. Maybe she has to get up and things like that, do something for

them, I don't know what it is, she don't want them to see her in this condition." Carer, MND104

This carer went on to say that it didn't matter because they were used to spending a lot of time together:

"It is actually, it's good yes I am retired, we have got the company of each other and before she fell ill we used to be together all the time." Carer, MND104

There was a suggestion that this service user was embarrassed to see other people though, and this would impact not only her, but her husband too.

CMT101 spoke more openly about being embarrassed about his disability. He had been reluctant to attend the temple because of the reaction he would get to his splints, but he had got used to it now:

"Somebody sees and they'll ask me what they are… now I'm quite open about it" Service user, CMT101

However, although he still participated in leisure activities, his embarrassment over his disability was still having an impact. He had a blue disabled badge as he had walking difficulties. However, when with friends, or meeting friends somewhere, he wouldn't use his badge:

"It's my friends sometimes, I get a bit embarrassed using it, they say, some of them might, well friends' friends acquaintances, what you got that for, you know the Asians, they're very nosey you see. What's that for? So I, I don't want to go through the story again and explain to them" Service user, CMT101

One service user (MND103) had stopped attending family events such as weddings and other celebrations. Her carer said that it was because most venues did not have proper disabled access, and they didn't want to worry about whether it would be suitable for to attend or not. The service user had expressed that she wanted to go, but didn't want to cause trouble:

"She wanted to go but then she thought it's better off not going" Carer, MND103

The carer did say that the change of scenery would have been nice for her, but also that she suffered panic attacks with large numbers of people, although he didn't explain when or why the panic attacks had started.

Therefore, many of these service users experienced isolation not only because of the disease progression, but possibly because of the stigma of disability.

One Asian carer was unclear as to why Asian families kept HD hidden. She agreed to an arranged marriage and only found out several years later that her husband had HD. She said that she didn't know what it was and by then had had two children with him. She was devastated when she found out. Her husband had died, and both of

her children had HD, and she was now caring for both of them. She said that she would never have had children with him had she known, and that HD should not be kept hidden within families. As this carer was so open about her children having HD, she was able to maintain some sort of social life, even though it had to change to suit the needs of her children.

5.7 Summary

It is clear from the data that there are some barriers and facilitators to care for the service user's journey through the health and social care system. However, language was not as significant a barrier in this study as it has been identified in the literature. Although all service users in this study were able to access primary care without difficulty, the gatekeeper role of the GP sometimes acted as a barrier to receiving further care. Once referred and diagnosed, a key worker, or care co-ordinator seemed to be helpful to the majority of service users and carers. One or two service users chose to go abroad when they were unclear about diagnosis, or the process of diagnosis. The belief that Asian families look after their own was also not apparent in this data; service users in this study sample had different circumstances when it came to support. The next chapter will discuss these findings and their implications for service design and delivery.

6. DISCUSSION

This study has highlighted that some barriers to accessing services and obtaining appropriate care still exist for BME service users, although for the clinical conditions focused on in this project, these barriers were not always evident to the same extent that they have been noted in the existing literature on BME access to healthcare services.

The main barriers to care identified by the literature were language and communication, information availability and knowledge/awareness of services, cultural factors and stigma. The results chapter has outlined how these barriers were evident during the participating service users' journey through the health and social care system, and the research identified additional barriers to care which are not extensively covered in the existing literature, such as expectations of care. There were also a number of facilitators to care access which improved the ability of individual services users and their carers to obtain appropriate care.

These findings will now be discussed under each of the identified barriers and facilitators to care. These were language, information and knowledge of services, culture and stigma, and expectations of care.

6.1 Language

In this study, language was not found to be as great a barrier as the literature suggested it would be, despite some service users being unable to communicate in

English. Those that did not speak English typically had family members that could speak on their behalf and communicate with healthcare professionals and service providers for them.

Although all service users were able to present in primary care without difficulty, the role of the GP as gatekeeper contributed to how quickly service users were referred to secondary care for further tests. Nazroo et al (2009) found that although BME service users did not have trouble accessing primary care, they did not have the same referral rates to secondary care as non-BME service users. However, they did not establish the reasons for the low referral rates identified amongst BME service users. In a healthcare landscape where resources and services are limited, GPs need to act as gatekeepers to a certain extent, and referrals to specialist services for further investigations and diagnostic testing cannot be made for all individuals who present to their GP with symptoms that are frequently seen in many commonly encountered illnesses.

However, it is possible that BME service users could have been denied appropriate referral because of communication difficulties – referral is typically made on the basis of the type, duration, extent and severity of symptoms being experienced by a patient, and if an individual is unable to communicate effectively with their GP, this may reduce the likelihood of referral for further investigations so that a definitive diagnosis can be obtained. Gill et al (2009) analysed the Health Survey for England and estimated that approximately 300,000 people were unable to speak any English at all. The nature of the neurodegenerative conditions assessed in this study means

that prompt referral and early diagnosis are essential so that service users and carers can be placed onto the correct care plan, and so that they can make preparations for the future. It is therefore crucial that service users are able to communicate effectively with their health professional. Although language was only overtly problematic in one instance in this study, some service users did express dissatisfaction with GP services. This echoes findings from Mead and Roland (2009) who found that BME service users evaluated primary care more negatively than White British service users. However, it is difficult to establish whether BME service users' dissatisfaction with GP services arose from the fact that they had been treated less well than their non-BME counterparts (or at least that they perceived this to be the case), or that their expectations of services were higher than they should have been, thus leading to inevitable disappointment and dissatisfaction. In this study, the service users that were dissatisfied with their GP did not feel as if they had been listened to, despite language and communication issues not being salient factors with these specific individuals.

Once service users had been referred to secondary care, their experiences of care varied by condition. Although prompt diagnosis of neurodegenerative conditions is in the National Service Framework for Long Term Conditions (2005), such conditions can pose significant diagnostic difficulties for neurologists and other clinicians. Genetic conditions such as HD can be easier to diagnose if there is a known history within the family. However, conditions such as MND can only be diagnosed when all other conditions with similar presenting symptoms have been ruled out. This often means months of tests, leaving service users and carers with the anxiety of not

knowing what is wrong. MSA is even harder to diagnose and no scans are currently available which can provide a definitive diagnosis. Most of the service users in this study understood that diagnosis was time consuming, and that other conditions would need to be ruled out first as this had been communicated to them by their neurologist. Good communication between service user and health professional is vital so that service users do not feel that nothing is being done, and it can help them to understand the limitations of current medical technology.

Two of the service users went abroad, despite being under the care of a neurologist in the UK. Language was not brought up as an issue because one service user attended appointments with an English speaking carer, and the other service user could speak English. However, one carer did state that they were able to gain a better understanding of the condition when they sought care abroad because it was explained to them in their own language. The other service user who had travelled overseas to access care stated that they were given a diagnosis and started on treatment immediately (although this was an incorrect diagnosis). There is some evidence to suggest that some BME service users and carers may have more faith in the healthcare system from the country they were born in (Lee et al. 2010). Although only two service users interviewed in this study actually went abroad to seek care, other service users in this study did suggest that there would have been a higher standard of care in their ‘home’ country. Although medical tourism is usually raised in the context of overseas nationals accessing the NHS for care that they are not directly entitled to, health and social care professionals should be mindful of the possibility of ‘reverse’ medical tourism, with individuals resident in the UK seeking

treatment overseas. Such seeking of alternative treatments could interfere with diagnoses and treatments that service users receive via the NHS. If conflicts arise, this could be detrimental to the service user and significantly affect their prognosis, particularly when individuals have received incorrect diagnoses following medical consultations abroad.

Service users and carers need to be encouraged to speak out and complain if they are unhappy with the care that they receive. Lawton et al (2006) stated that Indians and Pakistanis were grateful for the services they received because they were free, suggesting that they might be reluctant to complain if they were dissatisfied with any aspect of their medical care. However, health and social care services can only improve if service users are able to state what is wrong.

The service users that required social services care described a number of difficulties. These included making and maintaining contact with social services. The service users and carers who participated in this study came from a wide geographical area, and different service users described a number of different social services whose quality and mode of organisation appeared to vary from region to region. Social services are organised on an individual basis, and the stated experiences of service users varied considerably. One carer said that social services had provided her with a key worker, and she was able to telephone them whenever she needed to. It was important to her to have this because she was not confident with her ability to speak English. However, another carer in a different geographical area spoke about his frustration with social services because there was no key

worker who would be familiar with the history of the case, but instead a call-centre style telephone system which made accessing social services difficult and frustrating. Although this particular carer was fluent in English, it is not clear how the social service organised in this 'impersonal' manner could have dealt successfully with a situation where someone could not speak English fluently. Social services need to consider the limitations associated with the way in which service users and carers can access support, and need to make access more transparent to people who have language difficulties.

Another consideration for service users with language barriers is that the neurodegenerative conditions focused on in this study may cause speech impairments, and such impairments were evident in some of the service users interviewed during this research. Speech and language would be barriers to care in this instance. One service user was provided with communication equipment, but operating the equipment required him to be able to speak English. Although the equipment had been provided by a voluntary sector organisation, all providers of such equipment need to be mindful of the needs of BME service users who do not speak English, and any communication equipment would need to be tailored to other languages beyond just English.

6.2 Information and knowledge of services

All MND service users had been provided with a folder that contained information about MND, useful phone numbers, and the types of services that they might need. Not all service users wanted to know about MND and how it would progress, so did

not necessarily take advantage of this information, but the provision of the information was a significant potential facilitator of access to care. The service users who did make use of the information provided found it invaluable, with the phone numbers being highlighted by interviewees as particularly helpful. These same service users mentioned that having a key worker enabled them to access services with greater ease. The HD service users also had a key worker and were in touch with the HDA. The MND service worked very closely with the MNDA. As these are two large and relatively well-resourced organisations, they work closely with the NHS, and quite often, service users did not know if their key worker was employed by the NHS or by the voluntary sector. This suggests that the MND and HD services have been successful in providing a seamless and integrated service, something that has been encouraged by Government policy (Audit Commission 2005;Department of Health 2004). It also means that service users have access to a comprehensive service that can meet their needs, and without needing to negotiate care or service access from a number of separate agencies, something that could be more difficult for BME service users. With the less well-known conditions (PPS, CMT, and MSA), all of the service users had been given information about the relevant voluntary sector organisation that could provide more information and advice about the condition. As these organisations were smaller and often less well-established, they did not have the same capacity to work as closely with the NHS as the larger organisations, but the NHS had close enough links to be able to signpost service users appropriately.

As mentioned earlier, MND and HD service users were allocated a key worker who could advise them on how to access social services care. It was service user expectations that often led to dissatisfaction with the services provided (see section 6.4). One HD service user described her local social services working closely with the HD service, which made accessing social care easier.

However, the service users in this study heavily criticised social services for lacking transparency in the types of services they offered. There is an overlap here with the language and communication theme, as described in the literature, because materials written in English may prevent some people from being able to access relevant services. Alam et al (2011) reviewed the literature concerning BME service users' experiences of accessing diabetes related care and found that those service users that had language and literacy issues struggled to understand health information. Similarly, Ochieng (2013) reported that Black African migrants cited lack of literacy as a problem to accessing health promotion information. However, this issue was not solely about language; service users felt that social services staff often lacked the necessary knowledge, and could therefore not advise on what was available. Closely related to this issue was the finding that service users, despite the provision of basic written information, still experienced difficulties in seeking out more detailed information as they were often unaware of where to look. Although having a clear website that outlines available services and details how to access them is an important part of the functioning of any healthcare organisation, this is often of limited utility for service users that have difficulties with the English language, and service users may not always have access to the Internet. A survey on Internet access in UK

households (ONS, 2013) found that almost one in five households did not have Internet access.

The literature has identified that health education and health promotion activities were well received when targeted to BME groups at events that BME service users and carers attended (Ghouri, 2005). Information provided at this type of event may be more meaningful to service users and carers and may improve access to care as a result. It would then have the benefit of including service users that did not have access to the Internet, and would break down any fears that service users might have about accessing services. Hesselink et al (2009) found that ethnic health care advisors in the Netherlands were useful in canvassing the information needs of different ethnic minorities, and suggested that ethnic outreach workers should be ethnically matched to the community they are targeting (Hesselink et al. 2009). Any health education and training provided could potentially arm service users with enough information to have more direct involvement in their care, rather than being passive, although it must be borne in mind that for many service users with neurodegenerative conditions, physically accessing services and outreach events may be difficult due to mobility impairments. This highlights the importance of maintaining a wide breadth and scope of information provision methods, so that services are made accessible to the widest possible number of service users and carers.

Finding alternative ways to inform service users and carers of available services is vital to improve access to care. Liu et al (2012) found that health promotion strategies

that were successful for the general population could be equally effective in BME populations if they were adequately adapted ways that were meaningful to those populations. Although the alternative recruitment methods (attending religious places of worship, snowball sampling, health fair, media) attempted in this study were not very successful in recruiting participants to the research itself, the use of such methods did demonstrate the numerous ways that it is possible to engage with the BME community. BME groups, particularly at the temple visits, were interested in health, and in research, and so would be responsive to information about available services, especially if it is likely to benefit them directly. If services are to be responsive to their service user needs, they must seek novel ways of engaging with them in order to improve access to care and provide a more equitable service. Flanagan and Hancock (2010) suggested that services could engage with harder to reach groups by offering more flexibility, working in partnership with other organisations, and even involving service users in service development (Flanagan and Hancock 2010).

6.3 Culture and stigma

Cultural factors and stigma did emerge as themes in both the literature and the interviews undertaken for this study. These factors were evident primarily in relation to social isolation rather than preventing accessing to health and social care services. The majority of service users were willing to accept the help that was provided. However, one service user did say that he preferred to struggle and walk further than park in a disabled space when his friends or acquaintances were present. He stated that he felt embarrassed, and that he did not want to explain his disability to his

friends. This same service user also felt embarrassed initially about attending the temple because he was worried that people would ask questions about his condition. There were a few service users who had stopped attending religious, community or family events, although most of the service users did not offer specific reasons for this beyond simply stating that they did not feel like going.

Service providers should be aware of the very real possibility that service users and carers will become isolated as a result of dealing with a neurodegenerative condition, and this isolation could lead to worsening mental health. Mackenzie (2006) interviewed Eastern European and South Asian service users about their beliefs about dementia and found that they were keen to conceal it from the wider community. The South Asian carers were particularly concerned about damaging marriage prospects of other family members if it became common knowledge. Similarly, Shefer et al (2013) conducted focus groups with members of different BME communities to find out about stigma and mental health. Many participants believed that communities needed educating about mental illness, and that families would often try to hide a diagnosis of mental illness, and would not discuss it with anyone in the wider community. This often resulted in people seeking help too late (Shefer et al. 2013). This echoes the stigma attached to HD. One carer spoke about the lack of Asian people attending HDA events. She found these events helpful and questioned why people would want to conceal something so important, when support was available. She herself had been duped into marrying someone with HD, and whilst she would have stood by her husband, she said she wouldn't have had children as she wanted to stop this disease. Pinfold et al (2005) interviewed mental health

service users about stigma, and how it could be challenged. They suggested that stigma could be challenged on different levels, including providing information to family, through public health campaigns, and through improvements to services (Pinfold et al. 2005). This three-pronged approach could be used to tackle stigma that service users and carers with neurodegenerative conditions face. It would raise the profile of these conditions so that people would know that help was available, and more importantly, acceptable.

Providing education about different conditions, and addressing issues around stigma would be helpful because it might help more people come forward to seek help, and at an earlier stage in their disease progression. All of the service users in this study sample were already known to services, but health education and promotion would encourage those service users too afraid to seek help. The Expert Patient Programme (EPP) (NHS England, 2007) was set up to encourage service users with long term conditions to take more control and responsibility for their care, and to pass on that knowledge and experience to others. If a similar programme was established for carers of people with these neurodegenerative conditions, then it might break down some of the stigma and encourage people to access help and to gain confidence in dealing with their condition in social situations, thus potentially going some way towards reducing social isolation as well.

6.4 Expectations of care

A surprising theme that emerged was expectations of care. The literature suggested that BME service users were passive in their care, and that they failed to access

services because they had language difficulties; lacked the appropriate information, or they felt culture bound or stigmatised. Although these themes did emerge from the data, the service users and carers in this study were not passive, but instead had high expectations of care. The expectations were greater for social services than for the NHS. Most of the service users and carers in the study had accepted that there was little the NHS could offer other than maintenance and monitoring. However, social services provision was heavily criticised for not doing enough. Service users and carers expected more choice in how their homes would be adapted rather than being told what changes social services would offer.

The service users and carers may have been less critical about NHS care because it is free at the point of access, and because service users and carers understood the limited ability of medical services to treat and ameliorate their particular conditions. Social services care was viewed far more critically, and in several cases, this criticism appeared to stem from the fact that access to social services care was means tested. Those service users that were entitled to full care understood and appreciated the limits of services, even though one service user stated that they were going to try and ‘play’ the system. The service users that were required to contribute financially to their own care following social services means testing expected to have more choice in the type of care they received. The majority of carers were not happy with simply having a downstairs bathroom installed, something that they had said social services had agreed to do, with service user contributions. They wanted extensions to their property built instead, yet such extensive structural alterations were simply something social services could not offer. As social services care was

not dependent on medical and technological advances, service users and carers may have believed that social services care would be complete and non-questioning. When social services failed to deliver this expected level of care, service users and carers fought back, sometimes by contacting their local MP, until they reached some understanding of what social services would offer.

If information about social services and the services they provided was more accessible to BME service users and carers, these unrealistically high expectations may be moderated. The BME service users also stated that social services treated them with respect in terms of their ethnicity and culture, and that this was not problematic at all. However, some service users did feel as if they had to fight in order to receive any type of service. Fighting for care may not be unique to (these) BME service users. All patients who have neurodegenerative conditions, regardless of their ethnic background, have rapidly changing needs, and if social services do not respond to these changing needs, carers may be inclined to try and be more forceful because they feel they have no other choice. Seeing a loved one suffering might be enough to drive anyone to fight for better care, even if it is unavailable. One of the providers of social services demonstrated good practice for the management of service users with neurodegenerative conditions. They had a special team for people with life-shortening conditions (such as Alzheimer's disease and Huntington's disease), and understood that service users would require regular reviews and updates to their packages of care. If service users and carers felt that their condition and their individual situation were being taken seriously, then they might be more understanding of the limits of the system.

6.5 Strengths

There were a number of strengths to this study. First, this has furthered knowledge about access to health and social care for BME service users and carers with rare neurodegenerative conditions. Although the study sample was small, it has highlighted where service users and carers face difficulties, and has highlighted what improves access to care. It has also shown that BME service users and carers may be experiencing barriers to care that are not unique to the BME community; they may be experiencing barriers to care despite their ethnicity.

Second, this study has demonstrated that a number of recruitment strategies exist and can be used to recruit BME service users and carers. Although the most successful recruitment method was through the condition-specific clinics, some service users were recruited through the voluntary sector, and the other recruitment methods enabled greater understanding of different minority groups. It also demonstrated that BME communities are interested in research, and would want to contribute to research.

6.6 Limitations

There were a number of limitations to the study. First, the eligibility criteria for the study required service users to have a definitive clinical diagnosis of their condition, thus all eligible participants were already known to services. As the study set out to examine barriers and facilitators to care, it would have been interesting to interview service users that had not yet presented to the health and social care system, and

investigate their reasons for this. However, accessing such individuals would have been impossible within the scope of this study and with the recruitment methods employed. Despite potential participants being recruited through both the voluntary sector and temple visit, these individuals had to be excluded from the study as soon as they stated that they had not yet received a definitive diagnosis for their condition. One person had seen the study advertised via the voluntary sector, and he said that he had an appointment and was waiting to be diagnosed. Although it would have been interesting to include this individual within the study, if he had eventually received a diagnosis unrelated to the neurodegenerative conditions of interest in this study, the data would have to have been excluded from analysis, thus placing unfair participant burden onto an individual who would not have been eligible for the study.

Second, the depth of some of the data collected was limited by the sensitivity of the subject area. Despite undergoing training in undertaking interviews in sensitive subject areas, during the interviews, decisions frequently had to be made whether or not to pursue a line of questioning that was upsetting to the service user and carer. In many cases, it was decided that it would be more appropriate to change to a different topic rather than pressing an issue that was evidently upsetting to the service user or carer being interviewed. Although this approach left some questions unanswered, it was felt that this was preferable to upsetting the participants and risking a termination in the interview and potential withdrawal of the individual from the study. Kavanaugh and Ayres (1998) suggested methods for reducing the distress that could be caused by speaking about sensitive subject areas, including recognising what things in particular cause distress to the service user (Kavanaugh and Ayres 1998). In this

study, palliative care was a particularly sensitive area for service users and carers to speak about, especially for service users who were at an early stage of their condition, and who may therefore not have considered palliative care options, or who may have been deliberately avoiding consideration of this eventuality. Another sensitive area was asking service users to speak about changes to their lifestyle. Service users and carers often had to make extensive changes to their lifestyle, and whether this was related to increased disability, stigma, or both was often not clear, and it was felt that further probing may have resulted in the service user becoming upset and even alienated with the research process. Tracy (2010) described different principles that qualitative research should follow in order for it to be high quality. She suggested that qualitative researcher should consider situational ethics; that is to say that qualitative researchers should consider the situation in the field, constantly reflecting, and make an ethical decision based on that reflection (Tracy 2010). As soon as it became apparent that the questioning could potentially lead to the service user and carer becoming upset, it was stopped, as it was felt that the service user and carer wellbeing was the priority.

Third, it would have been interesting to obtain the perspective of health and social care professionals. Having perspectives from both sides would have provided a more complete picture of the type of care that is available, what potential barriers exist and what makes access to care easier within the context of often limited healthcare resources. The data did not criticise individual health and social care professionals, and instead found that they were responsive to the needs of BME service users and carers. So although the literature identifies that health and social care professionals

may not feel confident about dealing with BME service users, and that they would like more training, the findings from this study suggests that this was not the case. However, there is evidence to suggest that not everyone likes to complain for fear of reprisals. Wessel et al (2012) found that there was a reluctance to complain about healthcare for a number of reasons; including fear that future care would be negatively affected (Wessel et al. 2012). Kai et al (2007) suggested that health professionals should treat patients as individuals rather than focussing on ethnicity, as this would reduce stereotyping, and individual needs would be met (Kai, Beavan, Faull, Dodson, Gill, & Beighton 2007). It seems from this study data that this was happening already. However, had they been interviewed, health and social care professionals may have told a different story. Funding and time constraints made interviewing health and social care professionals unfeasible.

Fourth, recruitment was limited to only 15 service users and carers and spread across five separate conditions so the findings of this study are necessarily limited. Although all of the included conditions are neurodegenerative, they vary in their presentation and symptoms, and also vary by prognosis and how much they shorten life. Therefore, although some comparisons can be made in terms of access to services, difference in the clinical conditions themselves may have impacted on the types of barriers experienced by service users and carers. However, the only differences that emerged from the data were in relation to the genetic conditions (HD) versus the remainder of the conditions in speed of referral by the GP. If there had not been a known history of HD, these service users may have had similar experiences in rates of referral. In addition, once service users were in secondary care, and

receiving social services support, the condition itself did not appear to make a difference to the types of barriers that they experienced. A larger study with more participants may have noted differences between conditions which were not apparent in this small sample.

Related to recruitment, and mentioned briefly in the recruitment methods section, the interviewer's ethnicity may have affected recruitment. As some of the conditions are stigmatised, some service users may have been reluctant to contact the researcher, fearful that their condition would become public knowledge in their local community. Although the interviewer provided assurances of confidentiality, it may have been too great a concern for some people. Some of the literature identified that some service users were reluctant to use interpreters, and some disliked bilingual doctors because of fears of breaches in confidentiality (Lawton et al, 2006, Doshani et al, 2007). Conversely, there is evidence to support the reverse too; some service users value bilingual staff, and the interviewer's ethnicity may have been beneficial too, as it enabled them to relate to the service users and carers that did participate, and may have resulted in a more thorough interview than would have been achieved by an interviewer of a different ethnic background.

The service users that were recruited into the study varied considerably in their socio-demographic characteristics, and this may also limit the impact the results have. The majority of participants fell into the South Asian demographic, but there were also 'White Other' participants, and one who identified as Mixed Race. The service users' age varied considerably, as did their length of time resident in the UK and their

English ability. The only thing they did have in common was that they did not identify as White British and that they all had a neurodegenerative condition. All of these factors would have affected the extent to which they perceived and experienced barriers to care. However, this study was designed to investigate the experiences of all non-White British service users and carers, and focussing on one group would have prevented highlighting the different perspectives that emerged from the data. Indeed, it could be argued that the high degree of variability in socio-demographics, clinical conditions and ethnicities of participants in this study was a strength, as the participants represented a true cross-section of the types of individuals who need to access services when suffering from the conditions included in the study.

6.7 Conclusion

The results highlight a number of barriers and facilitators to accessing care. Although the aim of the study was to identify barriers and facilitators to health and social care for BME service users with rare neurodegenerative conditions, many of the barriers and facilitators could be equally applicable to all service users, as some of the identified problems were not related to ethnicity. Aside from the language barriers, knowledge and information about services could have been a universal problem. Although public bodies are required to be more transparent, there still seems to be a long way to go before they are able to deliver accurate information about what services are available. These services may also have to find novel ways to deliver information in order to capture the interest of BME service users and carers, and to make it culturally acceptable. Having co-ordinated care, or having a key worker seemed to help service users enormously, and made services more accessible. This

is particularly important to people who have neurodegenerative conditions because their needs change so rapidly, which in itself provides unique challenges to accessing appropriate care.

Service users and carers were all able to access primary care without any perceived difficulty, but some service users experienced difficulty with onward referral. Similarly, this could have been equally applicable to all service users with rare neurodegenerative conditions because many of the symptoms could be related to a number of things, such as ageing. GPs are in a difficult position, and waiting to see if symptoms subside is part of their role. The majority of service users were referred on once it became clear that something else was wrong.

Expectations of care emerged as a theme, and the data suggested that the service users in this study had much higher expectations of care than health and social care capacity could accommodate. Although service users and carers were generous about the NHS care they received, even if there were perceived gaps in their care, they may have had a greater understanding of the capacity issues, and the limited resources available in this context. There may also have been gratitude that services were free (Lawton et al, 2006) and there may have been an understanding about the limited technology, and medical advances with their individual conditions. The same was not true for social services care. As social services care is means tested, service users and carers may not have fully understood the capacity issues for social services, and the nature of the care they were able to provide. In addition, social services care does not rely on technological advances, and only relies on providing

adequate support, such as making homes adaptable. If there was more transparency, then service users and carers may have more understanding of the care they were provided with and thus more realistic expectations of what they should be entitled to. Importantly, this theme highlights that BME service users and carers are not passive beings in relation to their care, and health and social care professionals can feel confident that when required, people will speak up.
The informal support that service users received varied considerably, and demonstrates that stereotypes of BME service users 'looking after their own' is simply not true. Health and social care professionals need to be mindful of this, and treat all service users as individuals.

In future work, it would be helpful to interview health and social care professionals to understand what they believe to be barriers to care, and to see whether there are perceived gaps in training and to identify examples of good practice which would be amenable to being adopted more widely across health and social care services, for the benefit of patients.

It would also be interesting to follow several service users through a complete journey to understand the nature of barriers (and facilitators) to care at different stages of what may be a rapidly progressing illness. Information on the use of and access to palliative care was severely limited due to the sensitive nature of discussing such issues, but if a study was designed to specifically address this, it would help health and social care services to make services more individualised so

that all service users would have equal access to care at all stages of their illness, from initial diagnosis to end of life.

APPENDIX A

Authors and Year	Title	Objectives	Participants	Main findings
Alam,R.; Speed,S.; Beaver,K. (2012)	A scoping review on the experiences and preferences in accessing diabetes-related healthcare information and services by British Bangladeshis	This was a review paper to identify the preferences and experiences of British Bangladeshis in accessing diabetes-related care	British Bangladeshis. Studies had between 12 and 476 participants.	Language was a problem in relation to communication and literacy, and consequently it was difficult to understand health information. Many relied on local service provision as it was difficult to travel outside of the local area.
Almond,P.; Lathlean,J. (2011)	Inequity in provision of and access to health visiting postnatal depression services	This was a case study examining the equity of the provision of public health postnatal depression services.	20 health visitors, 6 managers, 12 English women, 9 Bangladeshi women, and 3 other personnel.	There was a policy on the provision of equitable services but health professionals did not feel that it met the needs of a diverse population. Health visitors did not feel equipped to treat diverse women.
Badger,F.; Clarke,L.; Pumphrey,R.; Clifford,C. (2012)	A survey of issues of ethnicity and culture in nursing homes in an English region: nurse	This survey explored ethnicity and culture in nursing homes in	Nursing home managers were surveyed and	101 surveys were completed and 13 interviews were conducted.

Authors and Year	Title	Objectives	Participants	Main findings
	managers' perspectives	England.	interviewed	Most people treated patients on an individual basis. Diverse staff did help, but some felt that training in end of life care was necessary
Bandesha,G.; Litva,A (2004)	Perceptions of community participation and health gain in a community project for the South Asian population: a qualitative study	Explores differences in perception of participation between lay and professional stakeholders of a community health project for South Asians in Manchester	Interviews with 13 professional stakeholders and 3 focus groups with Pakistanis, Indians, and Bangladeshis.	Lay people felt lack of cultural awareness and felt some professionals held stereotypical views. Professionals also difficult to engage.
Bowes, A.; Wilkinson,H. (2003)	We didn't know it would get that bad: South Asian experiences of dementia and the service response	To understand the experiences of Older south Asian people, their families and carers, and to explore central issue of service support.	Qualitative study: Interviews with 11 professionals working with people who had dementia, 4 case studies and their families and carers.	Difficulty in getting information once diagnosed, and residential care not seen as an option. Health professionals believed mainstream services were inappropriate and that the voluntary sector was a good way to engage

Authors and Year	Title	Objectives	Participants	Main findings
				with BME service users. Health professionals believed that they needed more training.
Bywaters, P.; Ali, Z.; Fazil, Q.; Wallace, L. M.; Singh, G, (2003)	Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement	To explore the reasons for low uptake of services	Interviews with 20 families (15 Pakistani and 5 Bangladeshi)	Parents had little information about their child's condition. Language barriers apparent. Shame and stigma – parents had felt shame, and had been on the receiving end of negative attitudes. Seeking help – Families information needs hampered by language barriers. Respite care not available at time which met families' needs e.g. someone wanted 6 weeks respite but was only available for one week at a time
Chauhan,U.; Baker,D.; Lester,H.;	Exploring uptake of cardiac rehabilitation in a	To explore the experiences of BME	Interviews with 12 Pakistani, 6 Indian	Previous negative experiences of healthcare

Authors and Year	Title	Objectives	Participants	Main findings
Edwards,R. (2010)	minority ethnic population in England: a qualitative study	service users following acute cardiac event and uptake of cardiac rehabilitation services	and 2 Bangladeshi service users	and communication difficulties related to non uptake of rehab. Gender and religious beliefs also factors .
Croot,E.J. (2012)	The care needs of Pakistani families caring for disabled children: how relevant is cultural competence?	To identify factors that Pakistani parents living in the UK and caring for children with learning disabilities felt were important components of their care	In depth interviews with 11 parents and one grandparent.	Being listened to by health professionals important. Language a barrier to explaining needs. Trust important and issues around honesty. They would have liked to have been informed about their child's disability from the start.
de Carvalho Leite,J.C.; de,L.Drachler; Killett,A.; Kale,S.; Nacul,L.; McArthur,M.; Hong,C.S.; O'Driscoll,L.; Pheby,D.; Campion,P.;	Social support needs for equity in health and social care: a thematic analysis of experiences of people with chronic fatigue syndrome/myalgic encephalomyelitis	To find out what the support needs are from health and social care for people with CFS. To find out where care inequities exist.	Focus groups and interviews with 35 people, eight of whom were from BME community.	People from ethnic minorities reported difficulties in accessing health and social care services, experiencing stigmatisation and stereotyping that did not fit their needs. Some non-White participants

Authors and Year	Title	Objectives	Participants	Main findings
Lacerda,E.; Poland,F.				felt they were treated differently by services because of their colour.
Doshani, A.; Pitchforth, E.; Mayne, C. J.; Tincello, D. G. (2007)	Culturally sensitive continence care: a qualitative study among South Asian Indian women in Leicester	Explore aims and experiences of incontinence and perceptions of care among south Asian women in Leicester.	Four focus groups with a bilingual moderator with South Asian women of different ages.	Barriers to seek help were embarrassment in discussing sensitive problems especially with male doctors. Women reported lack of available information. Lack of knowledge of services available. Wanted own nominated translator e.g. friend/relative rather than hospital based translator who may bump into social occasions. Written information would not raise awareness, but culturally relevant educational talks, media based discussions.

Authors and Year	Title	Objectives	Participants	Main findings
Edge,D. (2010)	Falling through the net - black and minority ethnic women and perinatal mental healthcare: health professionals' views	To investigate health professional views on perinatal healthcare for BME women	42 health professionals were interviewed	It was felt that training was not good enough, and participants expressed lack of confidence in identifying specific needs.
Elkan,R.; Avis,M.; Cox,K.; Wilson,E.; Patel,S.; Miller,S.; Deepak,N.; Edwards,C.; Staniszewska,S.; Kai,J.	The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature.	Aim to review published and unpublished work on BME experiences of cancer services	South Asians	Barriers included communication, lack of awareness of services, fear and stigma, and lack of cultural competence from providers
Free,C.; Green,J.; Bhavnani,V.; Newman,A.(2003)	Bilingual young people's experiences of interpreting in primary care: a qualitative study	To explore bilingual young people’s experiences of interpreting for family	77 interviews with 9-18 year olds (25 Vietnamese, 17 Bangladeshi, 18 Kurdish, 17 Eastern European).	Young people were used as interpreters because of lack of available interpreting services and by choice. Three factors led to problems with interpreting; health professional or patient communication skills, young peoples’ language skills, or the nature of the healthcare problem.

Authors and Year	Title	Objectives	Participants	Main findings
Gerrish,K.; Chau,R.; Sobowale,A.; Birks,E. (2004)	Bridging the language barrier: the use of interpreters in primary care nursing	To examine the utilisation of interpreting services by nurses	Focus groups with BME service users (Yemeni, Pakistani, Somali, Chinese and Bangladeshi), nurses, and link workers	BME service users were often not aware of interpreting services and relied on family. Some reported accessing primary care only in very serious cases because of language. Nurses also concerned about communication difficulties, but either had little awareness of interpreting services or were reluctant to use them because of financial reasons. Link workers believed they had a dual role to include interpreting, and felt that nurses did not know how to use interpreters effectively.
Jomeen,J.; Redshaw,M. (2013)	Ethnic minority women's experience of maternity services in England	To explore BME women's experiences of contemporary maternity care in	A UK wide survey, completed 3 months after birth. Open ended questions	60% of 368 women who identified as BME responded with open text. Themes - feeling cared for, expectations of care, staff

Authors and Year	Title	Objectives	Participants	Main findings
		England	thematically analysed.	attitudes, communication, ethnicity and culture, stereotyping
Kai, J.; Beavan, J.; Faull, C.; Dodson, L.; Gill, P.; Beighton, A. (2007)	Professional uncertainty and disempowerment responding to ethnic diversity in health care: a qualitative study	To understand how health professionals perceive their work with diverse communities	18 focus groups with 106 primary and secondary health professionals from different disciplines	There was professional uncertainty and health professionals felt disempowered. This was worrying because service users may not have been receiving care based on stereotypes. The authors suggested focussing on the individual and speaking to them about their care, rather than assuming cultural knowledge of the patient.
Karim,K.; Bailey,M.; Tunna,K. (2000)	Nonwhite ethnicity and the provision of specialist palliative care services: factors affecting doctors' referral patterns	To explore the views of doctors and palliative care consultants to understand use of palliative care services by BME service users	27 doctors interviewed - 15 consultants and 12 GPs	Underutilisation of day care and inpatient hospice services by BME. Doctors did refer their BME patients for hospice home care services

Authors and Year	Title	Objectives	Participants	Main findings
Katbamna,S.; Ahmad,W.; Bhakta,P.; Baker,R.; Parker,G. (2004)	Do they look after their own? Informal support for South Asian carers	To explore the experiences and needs of South Asian carers.	Focus groups and interviews with four main British South Asian communities (Punjabi Sikh, Pakistani, Bangladeshi, Gujarati Hindu).	Female carers struggled to get formal help from health and social care because of language and communication difficulties, and lack of knowledge of services. Some carers may decline help because of difficult family circumstances.
Lanceley,A.; Cox,C.L. (2007)	Cancer information and support needs of statutory and voluntary sector staff working with people from ethnically diverse communities	To identify the educational and support needs of health and social care staff working with people affected by cancer in a London Borough.	Interviews with staff and focus groups with patients from Asian communities	Many patients were not aware of services that were available to them. One patient said that they had to ask, and then they were told. This would be problematic if you didn't know what to ask for. There was a lack of trust with the GP sometimes, especially if they were of the same culture. There was worry about leak in confidentiality.

Authors and Year	Title	Objectives	Participants	Main findings
				Service providers suggested that lack of knowledge was as much to do with poverty, education, and social exclusion as much as cultural factors.
Lawton, J.; Ahmad, N.; Hanna, L.; Douglas, M.; Hallowell, N. (2006)	Diabetes service provision: a qualitative study of the experiences and views of Pakistani and Indian patients with Type 2 diabetes	To explore Indian and Pakistani patients' experiences of diabetes services	Interviews with 23 Pakistani and 9 Indian diabetes patients in Edinburgh	There was gratitude for free services. They did not like to use interpreters and preferred to use bilingual staff instead. Majority of services users went to services for detection and resolution of complications rather than advice on managing diabetes
Mackenzie, J. (2006)	Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK	To identify the support needs of family carers of people with dementia from South Asian and Easter European	11 Pakistani carers, 5 Indian carers, 4 Polish carers and 1 Ukrainian carer.	Eastern European participants believed dementia to be the effects of the war and were keen to keep the diagnosis within the family. Some described dementia in terms of

Authors and Year	Title	Objectives	Participants	Main findings
		communities.		physical problems to allay some of the stigma attached to it. There was a compromise between using services and saving face. South Asians viewed dementia as a mental illness and stigma was associated with religion. They were keen to conceal the diagnosis as there were fears that it could affect marriage arrangements.
Manthorpe, J.; Iliffe, S.; Moriarty, J.; Cornes, M.; Clough, R.; Bright, L.; Rapaport, J; and Oprsi (2009)	We are not blaming anyone, but if we don't know about amenities, we cannot seek them out: black and minority older people's views on the quality of local health and personal social services in England	To report on the outcomes of the National Service Framework for Older People	Consultations with older people from a variety of ethnicities (Irish, Indian, Yemeni, Afro-Caribbean, Bosnian, Nigerian, Chinese, Vietnamese and Punjabi)	1839 older people participated, with 30% describing themselves from minority. Problem with obtaining information on services and dearth of translation. Not just translation but content too.
McKeown, E.;	The experiences of ethnic	To compare the	National sample	363 BME and 4776 White.

Authors and Year	Title	Objectives	Participants	Main findings
Doerner, R.; Nelson, S.; Low, N.; Robinson, A.; Anderson, J.; Elford, J. (2013)	minority MSM using NHS sexual health clinics in Britain	experiences of ethnic minority and White MSM who attend NHS sexual health clinics in Britain	recruited through number of methods and men completed online survey which included questions about their experience of attending the clinic.	Indian/Pakistani/Bangladeshi more anxious about attending clinic. Afraid people in community would find out and uncomfortable in waiting area.
Merrell, J.; Kinsella, F.; Murphy, F.; Philpin, S.; Ali, A (2006)	Accessibility and equity of health and social care services: exploring the views and experiences of Bangladeshi carers in South Wales, UK	To identify the health and social care needs of Bangladeshi carers	Interviews with 20 Bangladeshi carers	Most carers had limited knowledge of available services, and those that did were concerned about whether they were acceptable in the Bangladeshi community. Language was a barrier to service access and informal interpreters widely used.
Merrell, J.; Kinsella, F.; Murphy, F.; Philpin, S.; Ali, A. (2005)	Support needs of carers of dependent adults from a Bangladeshi community	To find out what the health and social care needs are of Bangladeshi carers of dependent adults in South Wales.	Interviews with 20 Bangladeshi carers	Caring for dependent adult viewed positively despite difficult circumstances. There was some tension in accepting some forms of

Authors and Year	Title	Objectives	Participants	Main findings
				support. There was a lack of knowledge of available services.
Mir, G.; Sheikh, A. (2010)	'Fasting and prayer don't concern the doctors ... they don't even know what it is': communication, decision-making and perceived social relations of Pakistani Muslim patients with long-term illnesses	To explore the impact of religious identity on self management of long term conditions, patient-professional communication, and decision making.	In depth interviews	Religious identity plays a central role. Patients receive little support from professionals with regards to this aspect of their care.
Moffatt, S.; Mackintosh, J. (2009)	Older people's experience of proactive welfare rights advice: qualitative study of a South Asian community	Aimed to identify the barriers and facilitators to access welfare rights.	Interviews with 22 BME elders	Main barriers to access were lack of knowledge, language and personal circumstances. Carers did not have time to negotiate the benefits system. Stigma was attached to claiming benefits.
Mold, F.; Fitzpatrick,	Minority ethnic elders in	To review the	Systematic review.	This review found reports

Authors and Year	Title	Objectives	Participants	Main findings
J.M.; Roberts, J.D. (2005)	care homes: a review of the literature	literature in relation to BME older adults in care homes	Variety of participants	found a desire for ethnic elders to remain independent, and one study found that low uptake of respite services in Leicester nursing homes was linked to perceptions of being culturally inappropriate. Inadequate translation services.
Ochieng, B.M. (2013)	Black African migrants: the barriers with accessing and utilizing health promotion services in the UK	To explore the experiences of Black African migrants in accessing health promotion services	90 Black African migrants completed a survey	Participants were concerned about communication, about lack of literacy and their ability to access health promotion literature because of this.
Owens, A.; Randhawa, G. (2004)	It's different from my culture; they're very different: providing community-based, culturally competent palliative care for South Asian people in the UK	Exploratory investigation into ways in which professionals deal with difficulties, problems and ambiguities of culturally competent	10 interviews with professionals working in palliative care.	Perception by professionals that Asians look after their own and that they have lots of family around them. Professionals preferred to use family members rather than interpreters. Communication hampered

Authors and Year	Title	Objectives	Participants	Main findings
		practice.		packages of care.
Pattenden, J.F.; Roberts, H.; Lewin, R.J.P. (2007)	Living with heart failure; patient and carer perspectives	How patients with heart failure and their family carers cope with daily life.	Interviews with 36 patients and 20 carers. 7 out of these were BME.	Language difficulties created barriers to receiving telephone support. Patients who did not have English speaking relatives waited until the morning to speak to a GP who spoke their language. Access to an interpreter was essential when they had to have heart failure explained to them.
Raleigh, V.S.; Hussey, D.; Seccombe, I.; Hallt, K. (2010)	Ethnic and social inequalities in women's experience of maternity care in England: results of a national survey	To examine ethnic and social inequalities in women's experience of maternity care in England	Survey. Inequalities by ethnicity, partner status and education	26,325 women responded which was a response rate of 59%. Ethnic minority women more likely to access the service later than white British women, were generally more positive about the information they received, but more negative about the intra and postpartum care they

Authors and Year	Title	Objectives	Participants	Main findings
				received.
Randhawa, G.; Owens, A. (2004)	The meanings of cancer and perceptions of cancer services among South Asians in Luton, UK	To find about the experiences of South Asians in relation to cancer services	6 single-sex focus groups with Pakistanis, Bangladeshis, and Indians	Information about cancer would have been welcomed through community groups. Lack of information led to low awareness of cancer. Cancer was perceived as incurable as people often presented late to services.
Rhodes, P.; Nocon, A.(2003)	A problem of communication? Diabetes care among Bangladeshi people in Bradford	To examine the experiences of Bangladeshi diabetic patients in Bradford	12 in depth interviews with Bangladeshi diabetic patients	Informal interpreters used and preferred because seen as more private. Patients felt that they received poor quality care because of the attitude of staff.
Richardson, A.; Thomas, V.N.; Richardson, A. (2006)	"Reduced to nods and smiles": experiences of professionals caring for people with cancer from black and ethnic minority groups	To explore the views of health and social care professionals working with BME service users with cancer and their	Focus groups with health professionals working with service users with cancer.	Some participants found non-verbal ways of communicating but many found the lack of easy communication difficult to build a relationship with their

Authors and Year	Title	Objectives	Participants	Main findings
		needs for training.		patient. There were problems with interpreters – not being available on short notice, and not clear what they actually told patients. Some patients did not like to use interpreters from their own community because of confidentiality concerns.
Shefer, G.; Rose, D.; Nellums, L.; Thornicroft, G.; Henderson, C.; Evans-Lacko, S. (2013)	'Our community is the worst': The influence of cultural beliefs on stigma, relationships with family and help-seeking in three ethnic communities in London	To extend knowledge about cultural beliefs surrounding mental illness and to analyse how these beliefs influence experiences of stigma and relationships with family for individuals with mental illness	10 focus groups, 5 with mental health service users and 5 with laypersons from BME communities in London	4 different voices, and cultural beliefs influence help-seeking
Sin, C.H. (2006)	Expectations of support among White British and	To explore White and Asian older	Interviews with 7 white men, 10 white	High expectation among Asian Indian group of family

Authors and Year	Title	Objectives	Participants	Main findings
	Asian-Indian older people in Britain: the interdependence of formal and informal spheres	people's expectations of informal and formal support.	women, 12 Asian Indian men, and 9 Asian Indian women aged over 55.	support and state support with acknowledgement that family support may not materialise. White group high level of expectation of state support regardless of family support. Asian Indian reported lower usage and awareness of range of health and social care services.
St John, T. (2004)	Hidden Shame-A Review of the Needs of Asian Elders with Dementia and their Carers in a Kent Community	To identify need and barriers and facilitators to service access	Action research	Dementia viewed as a mental illness (madness). GPs found that most Asians did not know what dementia was, and accepted early symptoms as a normal part of ageing. Service providers believed low referral rates were because of stigma, confidentiality and language barriers. Carers believed language,

Authors and Year	Title	Objectives	Participants	Main findings
				culture and lack of GP referral to be the main barriers to access.
Thomas, V.N.; Saleem, T.; Abraham, R. (2005)	Barriers to effective uptake of cancer screening among Black and minority ethnic groups	To describe some of the factors that act as barriers to effective uptake of breast and cervical cancer screening services among BME in Brent and Harrow	Focus groups with 135 participants 85 women and 50 men	Barriers included poor knowledge, underlying health and cultural beliefs, attitudes, language, and unhelpful attitudes of HPs. Community based awareness education received well and beneficial.
Toni-Uebari, T.K.; Inusa, B.P.(2009)	The role of religious leaders and faith organisations in haemoglobinopathies: a review	A review to see what role religious leaders play in access to healthcare	Review paper. Variety of participants.	Involvement of religious leaders and faith organisations improved the level of acceptance in health related interventions
Turner, S.; Christie, A.; Haworth, E. (2005)	South Asian and white older people and dementia: a qualitative study of knowledge and attitudes	To see whether there were differences about what dementia was, care provided for dementia between White and Asian	Qualitative interviews with 96 White and 96 Asian	Asians had less knowledge about dementia, and more likely to see it as normal part of ageing. Less likely to think treatments were available, and thought that they should do the looking after.

Authors and Year	Title	Objectives	Participants	Main findings
		participants.		
Wilson, C.; Alam, R.; Latif, S.; Knighting, K.; Williamson, S.; Beaver, K. (2012)	Patient access to healthcare services and optimisation of self-management for ethnic minority populations living with diabetes: a systematic review	To evaluate evidence related to patient self-management and access to healthcare services for BME living with diabetes	Systematic review. Participants were Indian, Pakistani, Bangladeshi and Afro-Caribbean.	Access to healthcare hindered by lack of cultural sensitivity in service provision and under use of clinic based interpreters and community based services.
Worth, A.; Irshad, T.; Bhopal, R.; Brown, D.; Lawton, J.; Grant, E.; Murray, S.; Kendall, M.; Adam, J.; Gardee, R.; Sheikh, A. (2009)	Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study	To examine care experiences of Muslims and Sikhs in Scotland with life limiting illness and their families to understand the reasons for any difficulties with access to services and how these might be overcome.	In depth interviews, patients = 25, 18= family carers, 20= key health professionals	Misunderstanding about what hospice was for and whether they could cater for BME. There were language barriers and stigma relating to receiving outside help. Health professionals expressed lack of cultural awareness.

APPENDIX B

Topic Guide

Demographic data

Date of birth

Gender

Ethnicity

Education

Employment

Religion

Condition

Questions

1. When did you first become aware something was wrong?

Prompts: Did you notice something different about yourself?

Did anything happen to make you think something was wrong?

What did you do?

Prompts: Were you worried?

Did you seek any help? Where from? E.g. Friend, family, community leader.

2. When did you first go and see your GP?

Prompts: What happened to make you see the GP?

Did anyone come with you to the appointment?

Did the GP send you for some tests and did they explain what they were for?

3. What happened next?

Prompts: Were you sent for some tests?

Did the GP ask to see you again? Watch and wait?

4. Were you referred to a neurologist?

Prompts: How long did you have to wait?

Did the neurologist send you for tests?

5. What types of tests did you have?

Prompts: Were you sent for blood tests?

Did you have a scan?

Other neuro tests – lumbar puncture, nerve conduction tests, EEG

6. When did you first get diagnosed with your condition?

Prompts: How long ago did they tell you that you had your condition?

Did they explain to you what you had?

Did they explain to you what help you might need?

Did they explain to you the help that you could get health and social?

Were you given a follow-up appointment?

Were they helpful?

7. Was the diagnosis explained to you/ do you understand your diagnosis?

Prompts: Do you understand what your condition is and how it affects you?

Is there anything you don't understand?

Are you able to speak to your doctor/nurse if you need any advice?

Did someone attend the appointment with you, or did you want them to?

Were you offered a translator, or did you require on?

8. What types of services have you been accessing?

Prompts: Do you see a nurse, social worker, physio, OT.

Has anyone come to your house to see if you need to change anything?

Do you receive any benefits?

Does the person that cares for you receive any benefits?

Does anyone come into your house to help you in the morning?

Do you require any equipment such as a hoist, wheelchair etc.?

9. What type of services do you have access to?

Prompts: Eg physio, OT, specialist nurse, psychology.

Have you been offered a translator/do you require one?

(If appropriate) Have you been offered the option to be seen by female health workers?

10. Has anyone come to your house to assess your needs? How often has that happened?

Prompts: Do you have to pay for anything yourself?

11. Has your home been adapted at all?

Prompts: Do you have any grab rails. Have the doorways been widened?

Do you have a lift to get upstairs?

Has the bathroom been modified?

Have you had to move home?

12. Do you have anyone coming into your home to help you? Who cares for you most of the time?

Prompts: Does your carer receive carer's allowance?

13. Are there any services that you would like but do not currently receive?

Prompts: Can you request services that you think might help, or does the neurologist make suggestions?

14. Where did you find the most information about your condition?

Prompts: Did the doctor/nurse provide you with the most information?

Did you get information from the Internet?

Did you contact a voluntary organisation?

Did you want information?

15. Do your friends, family or local community know about your condition?

Prompts: Do you want them to know about it?

Have they been supportive?

Why don't you want them to know?

16. Are you able to do the things you did before this happened to you?

Prompts: Take part in local community activities

Other leisure activities

Work – did you have to leave employment?

How about the person that cares for you?

17. Do you know other people with this condition?

Prompts: Is it helpful to talk to them about it?

Would you like to get in touch with people that have this condition?

18. Is there anything that I haven't asked you about today that you would like to talk to me about?

APPENDIX C

Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions (RESULT)

Information Sheet

About the study

The RESULT study is looking at service provision for people with rare long-term neurological conditions. The National Service Framework for Long Term Neurological Conditions (NSF) has set out targets for services to improve care and treatment. However, little is known about the types of services people receive. This study aims to investigate the current provision of these services and how they need to change to meet the targets set out in the NSF.

Who can complete this study?

The study is specifically aimed at those receiving and using services for the following neurological conditions:

Motor Neuron Disease; Huntington's Disease; Progressive Supranuclear Palsy; Multiple System Atrophy; Post Polio Syndrome; Ataxia and Charcot MarieTooth Disease.

Whilst the questions are directly aimed at the User of the services, given the conditions it will cover we appreciate it may not always be possible for that person to actively take part without assistance.

We would welcome input from an advocate representing the User for example the next of kin; main carer; other relative or other representative.

Please note: Other representative can include requesting the help of a researcher from Birmingham University who will conduct an interview with the participant (see below for interview options).

Wherever possible the Advocate should complete the study having discussed the questions and answers with the User. However, it is important to us that we capture data covering all stages of illness and services. Therefore we will accept responses from advocates who assume consent unless the User is able to express their wish not to take part.

What will I have to do and how long will it take?

There are two ways that you can take part in this study. You have the choice of completing a one-off questionnaire, or taking part in a one-to-one interview.

There will be one questionnaire to fill out, and this should take approximately 30 minutes. The questionnaire will focus on the types of services you use, and the types of services you might like to see in the future.

The questionnaire will be available in a number of languages and formats.

There are a number of ways that the questionnaire can be accessed:

By post. The questionnaire can be posted to you, and a prepaid envelope will be provided for you to return it.

By email. The questionnaire can be emailed to you. A return email address will be provided and you will need a version of Microsoft Word to use it.

Via the web. You can complete the questionnaire on the web. This is the address for the website: www.xxxx.bham.ac.uk

By telephone interview. A researcher from the University of Birmingham would phone you at a time that was convenient for you.

By face-to-face interview. A researcher from the University of Birmingham will interview at a time and location that is convenient for you.

By web cam interview. A researcher from the University of Birmingham will interview you via a web cam at a time that is convenient for you.

Please note: Where a face to face interview is chosen an expected time of approximately 45 minutes would apply and the interview may be recorded with your permission.

What about confidentiality?

The information you supply about services through questionnaire and interview will be completely anonymous. Questionnaire data and any audiotaped information from interviews will be kept in a locked filing cabinet in Primary Care Clinical Sciences, at the University of Birmingham for 10 years. After this period, any information will be destroyed.

What are the benefits of taking part?

Services that people with long-term neurological conditions receive in the future will be based on the information you provide. This study will provide information on what services people are receiving, and how services need to change in order to meet the targets set out in the NSF.

Do I need to complete the whole study?

No. Whilst we are keen to get feedback on all areas of service levels from pre-diagnosis to palliative care you do not have to answer any questions that you do not feel comfortable with.

Do I have to take part in the study?

No. Participation is completely voluntary, and if you decide to change your mind at a later date, you can withdraw from the study without giving a reason.

Will I be told about the findings of the study?

At the end of the study, a report will be written for the Department of Health. If you would like to know the outcomes of the study, then please supply a name and contact details on the questionnaire, and a researcher from the University will inform you when the report is available. Alternatively, you can look at the National Service Framework for Long-term Neurological Conditions Research Initiative website (http://www.ltnc.org.uk/) where the outcomes of this study will be available. The findings of the study will also be available from charities' websites and newsletters.

If you have any questions about this study, or for more information, please contact

APPENDIX D

Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions (RESULT)

Carer Information Sheet

About the study

The RESULT study is looking at service provision for people with rare long-term neurological conditions. The National Service Framework for Long Term Neurological Conditions has set out targets for services to improve care and treatment. However, little is known about the types of services people receive. This study aims to investigate the current provision of these services and how they need to change to meet the targets set out in the National Service Framework (NSF).

I am a carer for someone who has a rare long-term neurological condition.

If you are the carer of someone with a long-term condition, you may be able to complete the questionnaire, or participate in an interview on his or her behalf if they give their consent to take part in the study.

Alternatively, if the person you care for is unable to consent to take part in the study, and if you think that it would be beneficial to them if they do take part, then you may give permission for them to take part in the study.

What will be involved and how long will it take?

There are two ways that you can take part in this study on behalf of the person that you care for. You have the choice of completing a one-off questionnaire, or taking part in a one-to-one interview for them.

There will be one questionnaire to fill out, and this should take approximately 30 minutes. The questionnaire will focus on the types of services the person that you care for uses, and the types of services they might like to see in the future.

There are a number of ways that the questionnaire can be sent out to you:

By post. The questionnaire can be posted to you, and a prepaid envelope will be provided for you to return it.

By email. If you would prefer, the questionnaire can be emailed to you. A return email address will be provided.

By telephone. A researcher from the University of Birmingham could phone you at a time that was convenient for you and could ask you the questions over the telephone.

Alternatively, you can opt for an one-off interview. The interview will be conducted by a researcher from the University of Birmingham and will last for approximately 45 minutes. With your permission, the interview will be audiotaped. There are a number of ways that the interview could be conducted:

A face-to-face interview at a time and location that is convenient for you.

A telephone interview. A researcher from the University of Birmingham will phone you at a convenient time.

By web cam. A researcher from the University of Birmingham will interview you via a web cam at a time that is convenient for you.

What about confidentiality?

The information you supply about services through questionnaire and interview will be completely anonymous. Questionnaire and interview data will be kept in a locked filing cabinet in Primary Care Clinical Sciences, at the University of Birmingham for 10 years. After this period, any information will be destroyed.

What are the benefits of taking part?

Services that people with long-term neurological conditions receive in the future will be based on the information you provide. This study will provide information on what services people are receiving, and how services need to change in order to meet the targets set out in the NSF.

What are the disadvantages of taking part?

There may be some questions about the services you receive that may be distressing to you and the person that you care for. However, you, or the person that you care for, do not have to answer any questions that you, or the person that you care for, do not feel comfortable with.

Do I have to take part in the study?

No. Participation is completely voluntary, and if the person that you care for, or you decide to change your mind at a later date, you can withdraw from the study without giving a reason.

Will I be told about the findings of the study?

At the end of the study, a report will be written for the Department of Health. If you and the person that you care for would like to know the outcomes of the study, then please supply a name and contact details on the questionnaire, and a researcher from the university will inform you when the report is available. Alternatively, you can look at the National Service Framework for Long-term Neurological Conditions Research Initiative website (http://www.ltnc.org.uk/) where the outcomes of this study will be available. The findings of the study will also be available from charities' websites and newsletters.

If you have any questions about this study, or for more information, please contact

APPENDIX E

Participant consent form

Study title: Result Study

Name of Chief Investigator:

Please read the points below and initial boxes to confirm you agree with each point.

I have read the information sheet (version ____ , dated ___ /___ /___) provided and have had the opportunity to ask questions about the study	☐
I consent to the interview being audiotaped and transcribed.	☐
I consent to taking part in this study	☐

Initial boxes

…….. …… ……..

Name of participant Date Signature

…….. …… ……..

Name of researcher Date Signature

APPENDIX F

Assent form

Study title: Result Study

Name of Chief Investigator:

Please read the points below and initial boxes to confirm you agree with each point.

I have read the information sheet (version ____ , dated ___ /___ /___) provided and have had the opportunity to ask questions about the study ☐

I consent to the interview being audiotaped and transcribed. ☐

I understand that participation is completely voluntary, and that I may withdraw from the study at any point, without having to give a reason ☐

I have read the carer information sheet (version ____ , dated ___ /___ /___) and participation in this study is in the best interests of the participant named below

_____

Initial

boxes

…….. …… ……..

Name of participant Date Signature

…….. …… ……..

Name of advocate Date Signature

…….. …… ……..

Name of researcher Date Signature

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